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AN ARGUMENT FOR THE INCLUSION OF CHILDREN WITHOUT MEDICARE

Rev. Raymond C. O'Brien*

I. INTRODUCTION

The issue is simple: Does America want healthy children and thus healthy adults? Achieving the goal of healthy children is complicated. It involves a critical examination of current statistics concerning children, a willingness to make radical decisions that will provide health care and a resolve to implement the decisions as quickly as possible. Statistics demonstrate that America's children are grossly underinsured. Congress is unwilling to make the radical decision necessary to provide universal coverage for children. A familiar vehicle for extending medical coverage is the best means through which health care coverage for children may be implemented. In short, if America wants healthy children, it should include children within the familiar confines of Medicare.

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Medicare itself is a nationwide health insurance program for the aged and certain disabled persons.¹ Congress enacted it in 1965 as a federal social insurance program to help older persons meet their health care expenses.² In 1994, the program will cover approximately 36.7 million persons with total expenditures of \$161.2 billion. Actual federal costs of the program total \$143.7 billion after deduction of the beneficiary premiums.³ The expenditure increased from 1993, when the actual federal cost was \$130.6 billion. Nonetheless, Congress has included provisions in the budget reconciliation acts enacted during the past decade that have reduced Medicare spending below levels that otherwise would have occurred. For instance, the Omnibus Budget Reconciliation Act of 1993 (OBRA 93) reduced Medicare spending by \$56 billion for fiscal years 1994 through 1998.⁴

Almost all Americans over the age of sixty-five automatically are entitled to Medicare Part A.⁵ Medicare Part B is voluntary; all Americans over the age of sixty-five and everyone enrolled in Part A may

¹ Part A of the Medicare legislation provides coverage, after a 24 month waiting period, for persons under age 65 who are receiving social security cash benefits on the basis of disability. Kidney transplants or renal dialysis also may be covered under the program. In 1993, Part A covered an estimated 31.4 million aged and 3.7 million disabled persons. See generally JENNIFER O'SULLIVAN, CONG. RES. SERV., HEALTH CARE FACT SHEET: MEDICARE 1 (Apr. 26, 1994) (FACT SHEET).

² DAVID KOITZ, CONG. RES. SERV., HEALTH CARE FACT SHEET—MEDICARE: ELIMINATION OF THE LIMIT OF THE AMOUNT OF EARNINGS SUBJECT TO THE HOSPITAL INSURANCE TAX 1 (Sept. 28, 1993).

³ For comparison, in 1989, parts A and B of Medicare cost \$120 billion and Medicaid cost \$54 billion. SELECT COMM. ON AGING, HOUSE OF REPRESENTATIVES, 101ST CONGRESS 2D SESS., MEDICARE AND MEDICAID'S 25TH ANNIVERSARY—MUCH PROMISED, ACCOMPLISHED, AND LEFT UNFINISHED ix (Comm. Print 1990).

⁴ MARK MERLIS ET AL., CONG. RES. SERV., MEDICARE: PRESIDENT'S FY 1995 BUDGET PROPOSAL, SUMMARY 1 (Feb. 25, 1994). Medicare Part A is financed primarily through a payroll tax levied on current workers and their employers. In 1994, employers and employees each paid a tax of 1.45 percent on all earnings. (The self-employed paid a single tax of 2.9 percent on earnings.) Part B is financed through a combination of monthly premiums levied on program beneficiaries and federal general revenues. In 1994, the premium was \$41.10. Beneficiary premiums represent about 25 percent of Part B costs. Federal general revenues pay for the remaining 75 percent. FACT SHEET, *supra* note 1, at 2.

⁵ Part A (Hospital Insurance) provides coverage for inpatient hospital services, up to 100 days of post-hospital skilled nursing facility care, home health services and hospice care. Patients must pay a deductible (\$696 in 1994) each time their hospital admission begins a benefit period. (A benefit period begins when any patient enters a hospital and ends when he or she has not been in a hospital or skilled nursing care facility for 60 days). Medicare pays the remaining costs for the first 60 days of care. The limited number of beneficiaries requiring care beyond 60 days are subject to additional charges. Patients requiring skilled nursing facility care are subject to a daily coinsurance charge for the 21st—100th day (\$87 in 1994). There are no cost-sharing charges for home health care and limited charges for hospice care. FACT SHEET, *supra* note 1, at 1.

enroll in Part B by paying a monthly premium (\$41.10 in 1994).⁶ Nonetheless, "the combined expenditures of social security and medicare are now higher than the taxes and premiums collected to support them, and are projected to remain higher indefinitely."⁷ Indeed, the current prognosis is that Part A of Medicare will become insolvent in 2001,⁸ due in part to a persistent high rate of inflation in the health care sector of the economy, growth in services provided, an aging population and the potential impact of the post-World War II baby boomers' retirement early in the next century. Dominant factors were rising operating costs for hospitals and a shift toward more expensive services.⁹ Indeed, analysts estimate that "the tax rate would have to be increased by 175 percent or program costs would have to be reduced by nearly 65 percent to restore actuarial solvency."¹⁰

Medicare is thus at a crossroads. Under the threat of insolvency, the trustees of the social security and medicare trust funds have recommended that Congress take action to control Part A and B costs "through specific program legislation and as part of enacting comprehensive health care reform."¹¹ This is significant in that the future is demanding change. This need for change is not predicated upon a conclusion that Medicare has not worked for America's elderly. Rather, having worked so well to ensure quality health care, the assets are depleted. But Medicare does work. It has a proven record of success and a bureaucratic organization administered by commercial insurers or Blue Cross or Blue Shield Plans¹² that, with specific program legislation and comprehensive health care reform, could incorporate

⁶ Part B (Supplemental Medical Insurance) provides coverage for physician services, laboratory services, durable medical equipment, outpatient hospital services and other medical services. The program generally pays 80 percent of Medicare's fee schedule or other approved amount after the beneficiary has met the annual \$100 deductible; the beneficiary is liable for the remaining 20 percent. *Id.*

⁷ DAVID KOITZ, CONG. RES. SERV., THE FINANCIAL OUTLOOK FOR SOCIAL SECURITY AND MEDICARE 1 (Apr. 15, 1994).

⁸ *Id.* at 5.

⁹ *Id.*

¹⁰ COMM. ON WAYS AND MEANS, U.S. HOUSE OF REPRESENTATIVES, 1994 GREEN BOOK: OVERVIEW OF ENTITLEMENT PROGRAMS 182 (1994) (GREEN BOOK). The aged and disabled that Medicare services also are spending an increased share of their income on health care. "In 1975, about 4.3 percent of enrollees' per capita income went to cover their share of acute health care costs under Medicare. By 2000, enrollees will have to pay an estimated 8.6 percent of their per capita income to cover their share of costs under Medicare." *Id.* at 878.

¹¹ KOITZ, *supra* note 7, at 6.

¹² FACT SHEET, *supra* note 1, at 2.

America's children.¹³ Again, the issue is whether America wants healthy children and thus healthy adults. Absorbing America's children into the Medicare system will ensure that they become just as healthy as America's elderly.¹⁴

Proposing Medicare inclusion for children is not a new concept. In 1991, the National Commission on Children recommended "extending Medicare's increasingly effective hospital and physician payment system to the new public program."¹⁵ The proposal envisions a public plan that protects pregnant women and children through a federal government guarantee of health insurance coverage "to those who are not covered under employer-based plans."¹⁶ It is not linked to welfare and would provide coverage for those who earn too much to qualify for Medicaid. Using Medicare would guarantee "payment rates high enough to attract physicians and other providers,"¹⁷ but "because Medicare payment rates are based on the program's experience with a predominantly elderly population, adjustments would be needed to ensure that health care providers who make children a priority are not adversely affected by the payment system."¹⁸ The Commission estimates that this Medicare proposal would assist in extending "health insurance coverage to the estimated 8.3 million children and 433,000 pregnant women who are currently uninsured."¹⁹

Congress has not taken any action on the Commission's proposal to include children within Medicare, but it has flirted with medical coverage for children and pregnant women through the introduction of various legislative initiatives,²⁰ and states have attempted experimental

¹³ Specific program legislation reforms would include possible revenue sources to finance the inclusion of children within Medicare. See, e.g., THE PEPPER COMM., U.S. BIPARTISAN COMM. ON COMPREHENSIVE HEALTH CARE, A CALL FOR ACTION App. F (1990) (proposal includes increases in various taxes as well as the medicare premium).

¹⁴ The increased longevity and health of the elderly is due in part to federal and state programs. "Expenditures for personal health care services for the elderly nearly quadrupled between 1977 and 1987, rising from \$43 billion to an estimated \$162 billion." GREEN BOOK, *supra* note 10, at 884. Federal and state programs account for two-thirds of estimated 1987 spending for the aged, and the most significant of these programs is Medicare, which pays for nearly half of the aged's health bill. Medicaid pays for about 12 percent. *Id.*

¹⁵ NAT'L COMM. ON CHILDREN, BEYOND RHETORIC: A NEW AMERICAN AGENDA FOR CHILDREN AND FAMILIES 143 (1991) (BEYOND RHETORIC).

¹⁶ *Id.* at 141.

¹⁷ *Id.* at 143-44.

¹⁸ *Id.* at 144.

¹⁹ *Id.* at 155.

²⁰ See, e.g., SEN. CHRIS DODD, CHILDREN AND PREGNANT WOMEN HEALTH INSURANCE ACT OF 1993, 103d Congress; SEN. JUDD ALLAN GREGG, PUBLIC HEALTH SERVICE ACT AMENDMENT,

projects.²¹ Nonetheless, the result is a continuation of inadequate or nonexistent care for children. Indeed, "one in eight U.S. children (8.3 million) had no health insurance coverage from any source throughout 1992."²²

Among uninsured children in 1992, nearly two-thirds were not poor, more than three-quarters were White, and nearly seven of ten were from married-couple families In fact, if one could identify a 'typical' uninsured child, he or she would be White, between the ages of six and 17, and living with married parents in a working family with a moderate but above-poverty income.²³

This surprising statistic results from the fact that "most parents who do not have health care coverage for their children work for small employers, in industries with seasonal or temporary employment patterns, or in occupations with less-skilled and fewer unionized workers."²⁴ This is why the National Commission on Children, President Clinton's health care reform and the Children's Defense Fund recommend that government and employers develop a universal system of health insurance coverage.²⁵ Such a proposal would reverse the trend that "three-quarters of a million fewer children now are covered by employment-based insurance than in 1987, even though the population of children has increased by more than 3.5 million."²⁶

Medicaid is equally egregious. As a cooperative federal-state program that gives financial assistance to states that choose to reimburse certain costs of medical treatment for needy applicants,²⁷ "Medicaid reaches only a fraction of the nation's low-income population—an esti-

103d Congress; REP. HARRY A. JOHNSTON, FULL-SERVICE SCHOOLS ACT, 103d Congress; SEN. JOHN MCCAIN, CHILD HEALTH CARE IMPROVEMENT ACT OF 1993, 103d Congress; SEN. DONALD W. RIEGLE, COMPREHENSIVE CHILD HEALTH CARE IMMUNIZATION ACT OF 1993, 103d Congress.

²¹ See, e.g., *Beno v. Shalala*, 30 F.3d 1057 (9th Cir. 1994) (reversing a denial of preliminary injunction enjoining California from enforcing experimental program designed to discourage poor families from moving to the state).

²² MARTHA A. TEITELBAUM, CHILDREN'S DEFENSE FUND, THE HEALTH INSURANCE CRISIS FOR AMERICA'S CHILDREN 1 (1994). Millions more actually lacked health coverage for one or more months, but 8.3 million had no health coverage for the entire year.

²³ *Id.* at 9. Inadequate health care results in part from the decreasing contribution of private health insurers to dependent coverage. "In 1980 40 percent of employers paid for dependent coverage in full; in 1990 only about one-third did." BEYOND RHETORIC, *supra* note 15, at 136. But approximately half of uninsured children live in families below the poverty level, and about two-thirds live in families up to 200 percent of the poverty level. *Id.* at 137.

²⁴ BEYOND RHETORIC, *supra* note 15, at 137-38.

²⁵ See *Id.* at 139-47; TEITELBAUM, *supra* note 22, at 9-17.

²⁶ TEITELBAUM, *supra* note 22, at 9-10.

²⁷ See, e.g., *Schweiker v. Gray Panthers*, 453 U.S. 34, 36 (1981).

mated 59 percent of poor children in 1991.”²⁸ One reason for the lack of Medicaid coverage is that eligibility for participation historically has been linked to receipt of Aid to Families With Dependent Children (AFDC). Congress has demanded that states phase in more children, yet “a poor child who is 10 years old today will never be covered.”²⁹ And children in some states are far worse off than children in others. “The percentage of children who are uninsured ranges from 5 percent in Connecticut and Minnesota to 23 percent in Texas.”³⁰

Finally, the Clinton Administration’s comprehensive plan to reform the nation’s health care system failed to pass the 103rd Congress. The plan would have guaranteed health care coverage to thirty-seven million persons who currently are uninsured. The worker’s employer would be required to pay eighty percent of the average premium cost. The remaining amount would be paid by the family unless the family’s income was below 150 percent of the poverty level. Then there would be a federal subsidy to offset some or most of this cost. State created regional health alliances would broker the cost and services contained within a mandated standard package. The package would include the following:

immunizations and well-child care, preventive dental care, physical checkups (including vision and hearing screening for children), in-patient hospital emergency services, acute care services, physician and other professional services, eyeglasses for children, mental health services, and prescription drugs.³¹

The Administration proposal also included plans for a National Health Service Corps, funding for clinics and the creation of new rural health initiatives.³² And while costs would be high for both the American taxpayer and the medically needy indigent, other plans suffer from

²⁸ BEYOND RHETORIC, *supra* note 15, at 136. Nonetheless, states such as Pennsylvania “will pay for insurance coverage for uninsured children younger than six with family income up to 185 percent of poverty and, to help fill in Medicaid’s coverage gap, for children ages 10 and 13 with family income up to 100 percent of poverty.” CHILDREN’S DEFENSE FUND, THE STATE OF AMERICA’S CHILDREN: YEARBOOK 1994 13 (1994) (YEARBOOK). Massachusetts, Vermont, Florida, Colorado, Maine, Washington and Minnesota have expanded children’s coverage as well. *Id.* at 13-14.

²⁹ *Id.*

³⁰ TEITELBAUM, *supra* note 22, at 24. In 1993, Oregon and Tennessee were given Medicaid waivers to expand coverage for uninsured persons, but what is seen as an effort to curtail costs may result in disproportional rationing of services for the poor. State programs must be monitored. See YEARBOOK, *supra* note 28, at 14-15.

³¹ *Id.* at 12.

³² *Id.*

the same impasse. Thus, in spite of good intentions that private insurers, Medicaid, and government proposals evidence, "many American children go without health care simply because of their family's income, because of where their parents are employed, or because of where they live."³³

This Article proposes that Medicare coverage for children is warranted because of the failure of private health insurance, Medicaid or universal health care coverage. Furthermore, Medicare is well-established and has absorbed less demanding, although specific, medical emergencies in the past. For example, "most people who need a kidney transplant or renal dialysis because of chronic kidney disease are, under certain circumstances, now entitled to benefits under Part A regardless of age."³⁴ In 1974, when "end stage renal disease" (ESRD) beneficiaries became entitled to Part A benefits, "it was assumed that program enrollment would level out at about 90,000 enrollees by 1995. That mark was passed several years ago, and no indication exists that enrollment will stabilize soon."³⁵ Diabetes, a disease associated with multiple health problems, is the primary cause for the increasing numbers of people in renal care.³⁶ Since 1983, there has been a dramatic increase in the number of kidney transplants.³⁷ The Medicare structure absorbed these specific health needs and provided beneficial relief to America's elderly. Now is the opportunity to include America's children.

Just as Medicare has addressed the specific geriatric infirmities of those over the age of sixty-five, so too can it address the particular pediatric infirmities of those under the age of eighteen. To argue that those aged sixty-five are entitled to Medicare because of a lifetime of payment into a tax base—and the ability to contribute a modest premium now—fails to recognize the future financial contribution of children if they receive adequate health care. Rather than discriminate based on ability to pay or past contribution, the impetus for Medicare eligibility results from the need for something so fundamental as health care. Just as there was a need for the care of America's elderly, so there is a need for America's children. Medicare is a proven method to address this need.

³³ BEYOND RHETORIC, *supra* note 15, at 118.

³⁴ GREEN BOOK, *supra* note 10, at 123.

³⁵ *Id.* at 134.

³⁶ *Id.* at 135.

³⁷ *Id.* at 137.

Specific elements of this need are in the benefits package assembled by the Clinton Administration.³⁸ But items such as immunizations and physical check-ups, to name two, are hardly new; and they are hardly unique to children. But there are some unique health care conditions affecting children that specifically justify their inclusion within the confines of Medicare. These are: I. Discrimination and Confusion; II. Racism; and III. Poverty. This Article's purpose is to argue that these three health care conditions prompt immediate inclusion of children within Medicare.

II. DISCRIMINATION AND CONFUSION

A. Aids and Discrimination

Throughout the last two decades of the twentieth century,³⁹ the burgeoning reports concerning AIDS⁴⁰ are strewn with minorities. These minorities include persons participating in an alternative sexual lifestyle, persons trapped in dire socioeconomic status or addicted to needle drugs, persons confined behind bars, persons receiving blood transfusions, homeless and women. The fact that many of these persons are also black or Hispanic contributes to the conclusion that AIDS has a predilection for minorities.⁴¹ It is not that AIDS is genetically prone

³⁸ See YEARBOOK, *supra* note 28, at 12.

³⁹ Although the disease that would eventually be called AIDS was present in America and other world countries before the 1980s, official recognition often is associated with the June 5, 1981 publishing of pneumocystis carinii pneumonia cases in the Centers for Disease Control (CDC) publication, MORBIDITY & MORTALITY WKLY. REP. The CDC then reported the first case of Karposi's sarcoma one month later, on July 4, 1981. Other indices were Dr. Michael Gottlieb's article on Pneumocystis carinii pneumonia in gay men and Dr. Alvin Friedman-Kien's article on Karposi's sarcoma in the *New England Journal of Medicine*. See generally, RANDY SHILTS, AND THE BAND PLAYED ON 1-112 (1987). By late 1993, the American Association for AIDS Research (AMFAR) listed opportunistic infections extending from aspergillosis to wasting syndrome. See AMFAR, AIDS/HIV TREATMENT DIRECTORY 7 (June 10, 1994).

⁴⁰ AIDS is a misleading term. HIV infection is more descriptive. The former is characteristic of that stage of HIV infection identified with the presence of opportunistic infections. HIV is a much longer period of time: from seroconversion to the actual onset of opportunistic infections. See generally Giuseppe Pantaleo et al., *The Immunopathogenesis of Human Immunodeficiency Virus Infection*, 328 NEW ENG. J. MED. 327 (1993) (excellent article describing the mechanism of the disease in the context of time and event). Nonetheless, because of public familiarity with the term AIDS, I shall use it within this Article, yet with this proviso: "The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on the later stages of the disease." REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC XVII (1988).

⁴¹ A description of persons with AIDS (PWA) would include the following: Most HIV-infected persons are between 17 and 55 years of age, an age span that constitutes about 55% of the population. With a male-to-female predominance prevalence typically of at least 4 to 1, the preva-

to infect persons who are homosexual, drug users, prostitutes, the poor, female or hemophiliacs. God did not do it. There is no AIDS-friendly organism imbedded in the genetic structure of these persons. Rather, AIDS is associated with their status—the status of being a sexual minority, socio-economically depressed or handicapped.⁴² That this status is identifiable and so little is being done to address the health care and social conditions that will surely result in further discrimination, suffering and death—the essence of a discrimination.

The status of being a minority, poor or handicapped is routine in America. "Growth in real wages virtually halted in 1973, and families today spend a higher proportion of their incomes on housing, transportation, health care, higher education, and taxes. Poverty rates among young families have almost doubled since the 1960s."⁴³ And the composition of these poor families has changed too:

Today, one in four children in the United States is raised by just one parent, usually a divorced or unmarried mother. Many grow up without the consistent presence of a father in their lives. One of every five children lives in a family without a minimally decent income. Many of these families are desperately poor, with incomes less than half the federal poverty level. Each year, half a million babies are born to teenage girls ill prepared to assume the responsibilities of parenthood. Most of these mothers are unmarried, many have

lence rate might be expected to range from 1.2% to 1.8% for men and from 0.3% to 0.4% for women. Data from childbearing women range from 0.1% in California, Colorado, Michigan, New Mexico and Texas to 0.2% in Massachusetts, 0.5% in Florida and New Jersey and 0.7% in New York. For predominantly male prisoners in 15 state correctional systems, who should over-represent HIV prevalence because of more frequent IV-drug use, data range from 0 to 15%, with a median of 0.9%. The ratio of AIDS case incidence is 3.2 to one for blacks and 2.8 to one for Hispanics compared with whites. CDC, *AIDS and the Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 11 (Supp. No. S-4 1989). And "[f]ollowing the 1993 expansion of the AIDS surveillance case definition, the number of AIDS cases reported among racial/ethnic minorities in 1993 increased 135% over that in 1992, while the number among whites increased 114%." CDC, *AIDS Among Racial/Ethnic Minorities—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 644, 653 (1994).

⁴² When the term "handicapped" is used, it is primarily intended as being used in conjunction with the Americans With Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101-12213 and 47 U.S.C. §§ 225, 611 (1991). Additional rights derived from § 504 of the Rehabilitation Act of 1973 or the Emergency Medical Treatment and Active Labor Act, 42 U.S.C.A. § 1395dd (West 1992), are ancillary.

⁴³ BUREAU OF THE CENSUS, U.S. DEPT. COMMERCE No. 168, CURRENT POPULATION REPORTS. 65 (1990). See also GREEN BOOK, *supra* note 10, at 1156 (Between 1959 and 1969, the poverty rate in the United States declined dramatically. By 1971 it had increased slightly, and then it decreased again during 1972-73, to a point when, at 11.1 percent, it was the lowest poverty rate in a 24 year period. After 1978, the poverty rate rose steadily, and in 1992, the rate was 14.5 percent, or 36.8 million persons.). See also Guy Gugliotta, *Number of Poor Americans Rises for 3rd Year*, WASH. POST Oct. 5, 1993, at A6.

not completed their education, and few have prospects for an economically secure future.⁴⁴

It is important to identify the parameters of families affected by the status of color, poverty and handicap. As the disease shifts from affecting white, middle-class homosexuals⁴⁵ to women, and especially minority women,⁴⁶ women will be the single most affected group of persons infected with HIV, and with them their children. These women and their children are not new to the AIDS pandemic, but public awareness has been non-existent, and there been no orchestrated public response.⁴⁷ Therefore it is important to identify their existence.

According to Dr. Karen Hein, Professor of Pediatrics and Associate Professor of Epidemiology and Social Medicine at Albert Einstein College of Medicine, Bronx, New York: "The new face of AIDS world-

⁴⁴ BEYOND RHETORIC, *supra* note 15, at 4.

⁴⁵ The proportion of white homosexual or bisexual men diagnosed as HIV-positive or with AIDS has been decreasing for five years. This is due in part to actual fewer numbers of men testing positive or being diagnosed, and it is due to the explosion of HIV infection in the heterosexual community because of shared needles and sexual activity with persons who are involved with drugs. See AIDS: THE SECOND DECADE 4-6 (Heather G. Miller et al. eds., 1990); see generally CDC, *AIDS and the Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 1, 12 (1989); Paul Cotton, *U.S. Sticks Head in the Sand on AIDS Prevention*, 272 JAMA 756 (Sept. 14, 1994); Sten H. Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034-35 (1993) ("A plateau in annual AIDS cases has occurred among gay men, attributable to benefits of prophylactic chemotherapy and reduced HIV transmission."); Peter Aggleton et al., *Risking Everything? Risk Behavior, Behavior Change, and AIDS*, 265 SCIENCE 341 (1994); Lawrence K. Altman, *Who's Stricken and How: AIDS Pattern is Shifting*, N.Y. TIMES, Feb. 5, 1989, at A1.

⁴⁶ See CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 547, 549 (1993). This article states,

From 1991 through 1992, larger proportionate increases in reported cases occurred among women (9.8%) than among men (2.5%). For women, rates were higher for non-Hispanic blacks and Hispanics (31.3 and 14.6 per 100,000 population, respectively) than for non-Hispanic whites (1.8) The number of reported cases among homosexual/bisexual men decreases during 1992

⁴⁷ For an example of the statistical evidence of the effect of AIDS on women, see generally Andrew Avins et al., *HIV Infection and Risk Behaviors Among Heterosexuals in Alcohol Treatment Programs*, 271 JAMA 515 (1994); Marsha Goldsmith, "Invisible" Epidemic Now Becoming Visible as HIV/AIDS Pandemic Reaches Adolescents, 270 JAMA 16 (1993); Richard North & Karen Rothenberg, *Partner Notification and the Threat of Domestic Violence Against Women with HIV Infection*, 329 NEW ENG. J. MED. 1194 (1993) ("Women now represent 13 percent of reported cases. Approximately 80,000 women of childbearing age are infected with the Human immunodeficiency virus (HIV), and as many as 14,000 women will have been given a diagnosis of AIDS by the end of 1993."); Richard Selik et al., *HIV Infection as Leading Cause of Death Among Young Adults in US Cities and States*, 269 JAMA 2991 (1993); Sten H. Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034 (1993).

wide is the face of teenaged girls."⁴⁸ The statistic that, among young women, AIDS is the leading cause of death in nine cities in America reflects this fact.⁴⁹ Such statistics should not come as a surprise when scientists have known since the early 1970s that "sexually transmitted diseases (STDs) (including human immunodeficiency virus infection and acquired immunodeficiency syndrome), unintended pregnancies, and other problems that result from sexual activity have increased among adolescents in the United States."⁵⁰ Approximately one million adolescent girls become pregnant each year, and eighty-six percent of all STDs occur among persons aged fifteen to twenty-nine years.⁵¹ Further, STDs and AIDS complement each other.⁵²

⁴⁸ CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1991*, 41 MORBIDITY & MORTALITY WKLY. REP. 463, 466 (1992) ("STD rates have increased among women, certain racial/ethnic minorities, and persons in younger age groups," indicating unprotected sexual practices and increased availability to transmission.); Goldsmith, *supra* note 47, at 16-19 ("During 1991, the proportions of reported AIDS cases increased most among women, blacks and Hispanics, persons exposed to HIV through heterosexual contact, persons in the South."). See generally CDC, *Condom Use Among Male Injecting-Drug Users—New York City, 1987-1990*, 41 MORBIDITY & MORTALITY WKLY. REP. 617, 617-20 (1992); ("Most women with AIDS were black or Hispanic (72%); residents of large metropolitan areas (73%), especially cities along the Atlantic coast; and of reproductive age (15 to 44 years) (85%).").

⁴⁹ Selik, *supra* note 47, at 2991. "Infection with HIV has become the leading cause of death among young adults in an increasing number of U.S. cities and states, in which the proportion of deaths due to HIV ranges from 14% to 70%, depending on the sex and racial/ethnic group. Among young women, HIV infection has had the greatest impact on mortality in several East Coast states (Connecticut, Florida, Maryland, New Jersey, and New York)." *Id.* at 2994.

⁵⁰ CDC, *Sexual Behavior Among High School Students—United States, 1990*, 40 MORBIDITY & MORTALITY WKLY. REP. 885, 885 (1992). More recently, see CDC, *Health-Risk Behaviors Among Persons Aged 12-21 Years—U.S., 1992*, 43 MORBIDITY & MORTALITY WKLY. REP. 231-35 (1994); CDC, *Update: Impact of the Expanded AIDS Surveillance Case Definition for Adolescents and Adults on Case Reporting—United States, 1993*, 271 JAMA 976 (1994); Sten Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034, 3034-35 (1994).

⁵¹ CDC, *Sexual Behavior Among High School Students—United States, 1990*, 40 MORBIDITY & MORTALITY WKLY. REP. 885, 885 (1992). Birth rates for these young women were highest among Hawaiians, black non-Hispanics and Hispanics. "In particular, rates for teenaged Mexican Americans, Puerto Ricans, black non-Hispanics, and Hawaiians were each two to three times the rates for white non-Hispanics, Cuban Americans, and Filipino Americans and up to 31 times the rates for Chinese Americans, Japanese Americans, and 'other' Asians/Pacific Islanders." CDC, *Childbearing Patterns Among Selected Racial/Ethnic Minority Groups—United States, 1990*, 42 MORBIDITY & MORTALITY WKLY. REP. 398, 399 (1993). See also CDC, *Childbearing and Contraceptive-Use Plans Among Women at High Risk for HIV Infection—Selected U.S. Sites, 1989-1991*, 41 MORBIDITY & MORTALITY WKLY. REP. 135 (1992); CDC, *HIV-Risk Behaviors of Sterilized and Nonsterilized Women in Drug-Treatment Programs—Philadelphia, 1989-1991*, 41 MORBIDITY & MORTALITY WKLY. REP. 149 (1992).

⁵² The connection between women and children is made by Professor Crossley:

As HIV infection among women increases, so does infection among children. It is estimated that more than three quarters of the women diagnosed with AIDS in the United

Since the change in the case definition of AIDS on January 1, 1993, the statistics will include more women because cervical cancer is now defined as an opportunistic infection indicating the onset of AIDS.⁵³ The increase in numbers will result in more awareness of the plight of women with AIDS, and the numbers will reflect a truer picture of the actual impact the disease is having on women. This also should increase attention directed towards infants with AIDS.⁵⁴

Looking beyond the horror of increasing numbers of teenage girls progressing through HIV infection and probable death, another group of persons looms large in the panoply of those AIDS affects most. That group is infants with AIDS. Specifically, the group consists of children who acquired HIV from their infected birth mother.⁵⁵ This is a group under-noticed and extremely vulnerable. They are most often referred to as "boarder babies," but the clinical term is "perinatally infected infants," and the problem is known as "pediatric AIDS." As of June 1993, 4710 cases, or 87.5%, were attributable to perinatal infection,"

States are of childbearing age, and a 1989 study estimated the incidence of HIV infection in women actually giving birth in that year to be 1.5 women out of 1000 nationwide.

Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1591 (1993).

⁵³ The prior method of defining AIDS for case surveillance, published in 1987, excluded some opportunistic infections particular to women. The new definition includes all HIV infected persons with severe immunosuppression, pulmonary tuberculosis, recurrent pneumonia or invasive cervical cancer. See CDC, *Impact of the Expanded AIDS Surveillance Case Definition on AIDS Case Reporting—United States, First Quarter, 1993*, 42 MORBIDITY & MORTALITY WKLY. REP. 308, 308 (1993).

⁵⁴ See, e.g., CDC, *Projections of the Number of Persons Diagnosed with AIDS and the Number of Immunosuppressed HIV-Infected Persons—United States, 1992-1994*, 41 MORBIDITY & MORTALITY WKLY. REP. 1 (1992); Barbara Vobejda, *A Legacy of AIDS: Orphans*, WASH. POST, Mar. 29, 1994, at A3.

⁵⁵ It is estimated that between 13% and 40% of infants who are born to HIV-infected mothers will acquire HIV either in utero or at the time of delivery. Perinatal HIV infection progresses more rapidly than HIV infection in adults, with most perinatally infected infants developing symptoms of advanced infection in the first 18 months of life. Edward Connor, *Advances in Early Diagnosis of Perinatal HIV Infection*, 266 JAMA 3474, 3474 (1991); for most recent data, see CDC, *Update: Impact of the Expanded AIDS Surveillance Case Definition for Adolescents and Adults on Case Reporting—United States, 1993*, 271 JAMA 976 (1994). As to the exact moment of transmission, current thinking is that "there is no consistent spread of HIV across the placenta during maternal viraemia, and indicate that in most cases transmission occurs close to or at delivery." A. Ehrnst et al., *HIV in Pregnant Women and Their Offspring: Evidence for Late Transmission*, 338 LANCET 203, 206 (1991); see also Richard Markham et al., *Maternal IgG1 and IgA Antibody to V3 Loop Consensus Sequence and Maternal-Infant HIV-1 Transmission*, 343 LANCET 390 (1994); Richard Semba et al., *Maternal Vitamin A Deficiency and Mother-To-Child Transmission of HIV-1*, 343 LANCET 1593 (1994).

[but] experts estimate that for each reported case of AIDS, another two to ten children are infected with HIV."⁵⁶

There is little focus on these HIV-infected babies, the poverty, status, color or handicap that engendered the unique moral and legal dilemma that society faces in confronting what to do about the burgeoning number of HIV-infected infants. Few articles discuss the ethical, moral or legal options surrounding perinatally infected infants.⁵⁷ Few legal decisions even raise the issue of selective nontreatment of adults, let alone children.⁵⁸ Indeed, these infants with AIDS have been termed the "ultimate minority."⁵⁹

Some efforts, such as the Ryan White CARE funds available to communities,⁶⁰ have attempted to attach infants with AIDS to existing community programs, and of course, the National Commission on Children's proposal suggested expanded Medicare coverage.⁶¹ Nonetheless, these infants suffer from discrimination through selective nontreatment,⁶² reluctance to provide protection under the Americans With Disability Act (ADA), actual and constructive child abuse and society's moral and ethical reluctance to address the problem.⁶³

Reports indicate that the drug AZT that doctors give to pregnant women may in fact prevent transmission of the virus to an infant.⁶⁴ The

⁵⁶ Crossley, *supra* note 52, at 1593-94.

⁵⁷ For an excellent article discussing the disability discrimination suffered by HIV-infected infants allowed to die because of selective nontreatment, see *id.* at 1581. See also Abigail English, *The HIV-AIDS Epidemic and the Child Welfare System: Protecting the Rights of Infants, Young Children, and Adolescents*, 77 IOWA L. REV. 1509 (1992).

⁵⁸ See, e.g., *Glanz v. Vernick*, 750 F. Supp. 39, 41 (D. Mass. 1990) (holding that refusal to perform elective surgery on HIV-infected person was actionable under the Rehabilitation Act).

⁵⁹ Crossley, *supra* note 52, at 1604 (quoting CHILDREN AND HIV INFECTION: HEARINGS BEFORE THE HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS SUBCOMMITTEE OF THE HOUSE COMM. ON GOVERNMENTAL OPERATIONS, 101st Cong., 1st Sess. 20, 31 (1989) (statement of Gwendolyn V. Scott on behalf of the Pediatric AIDS Coalition)).

⁶⁰ See generally Raymond C. O'Brien, *A Legislative Initiative: The Ryan White Comprehensive AIDS Resources Emergency Act of 1990*, 7 J. CONTEMP. HEALTH L. & POL'Y 183-205 (1991).

⁶¹ See BEYOND RHETORIC, *supra* note 15, at 143-44.

⁶² As a recent example of selective nontreatment as a judicial issue, see *In re Baby K*, 16 F.3d 590 (4th Cir. 1994) (holding that the Emergency Medical Treatment and Active Labor Act requires that a hospital provide stabilizing treatment for an emergency medical condition, to include an infant that is permanently unconscious).

⁶³ In addressing these issues of victimization, emphasis must be given to the research and analysis of Professor Mary A. Crossley. See generally Crossley, *supra* note 52.

⁶⁴ See *AIDS Drug May Prevent Transmission to Fetus*, WASH. POST, Feb. 21, 1994, at A12. The concern is over long-term toxicities affecting the children, but the National Institute of Allergy and Infectious Diseases canceled the placebo study and directed that all pregnant women be

Centers for Disease Control (CDC) has provided general principles regarding treatment with this objective in mind.⁶⁵ Yet, "approximately 10,000 or more children are believed to be infected"⁶⁶ and more certainly will be born because of the unavailability of AZT or other factors mitigating the mother's taking of the drug, cost being the most important of these factors. Regardless of the vast number of infants born each day in foreign countries to HIV-positive women,⁶⁷ it is absolutely safe to say that there will always be infants subject to discrimination simply because they have AIDS. Medicare coverage could make AZT available to these infants in gestation and thus could provide a modicum of care upon birth, no matter what the infants' HIV status.

B. *Aids and Confusion*

Infants with AIDS almost always are products of women who have suffered discrimination, racism and poverty. Mothers pass this on to these infants. But when AIDS enters the picture, another factor does as well: confusion. If the mother were African-American, Hispanic, poor, living in a particular inner city or even a prostitute, she would at least have an identity. People and agencies would respond to her as a person

given the drug. See also Lisa Teachey, *Some Houston Doctors Offering AZT to Pregnant Women at Risk of AIDS*, THE HOUSTON CHRON., Feb. 22, 1994, at A20; Martin Walker, *Drug Saves Some Babies From HIV During Pregnancy*, THE OTTAWA CITIZEN, Feb. 22, 1994, at A10. Studies continue to indicate AZT effectively reduces transmission from mother to child. See, e.g., Ronald Bayer, *Ethical Challenges Posed by Zidovudine Treatment to Reduce Vertical Transmission of HIV*, 331 NEW ENG. J. MED. 1223 (1994); Edward M. Connor, et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 With Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173 (1994); Martha F. Rogers et al., *Reducing the Risk of Maternal-Infant Transmission of HIV: A Door is Opened*, 331 NEW ENG. J. MED. 1222 (1994).

⁶⁵ See CDC, *Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus*, 43 MORBIDITY & MORTALITY WKLY. REP. RR-11 (1994); CDC, *Zidovudine for the Prevention of HIV Transmission from Mother to Infant*, 43 MORBIDITY & MORTALITY WKLY. REP. 285 (1994).

⁶⁶ CDC, *Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus*, 43 MORBIDITY & MORTALITY WKLY. REP. RR-11 (1994).

⁶⁷ According to Michael Merson, director of the World Health Organization's Global Program on AIDS, "Asia's epidemic may ultimately dwarf all others in scope and impact." Editorial, *AIDS: The Third Wave*, 343 LANCET 186, 188 (1994). Comparing areas of the world where AIDS has had significant impact, "the African experience suggests that large numbers of children will be orphaned. Poverty will increase, together with a breakdown in education and diminished food production as the work force falls ill. The resulting economic costs will further strain an already brittle health-care system." *Id.* at 187. For suggestions as to how to prevent spread of the disease on a geographical scale, see Michael Balter, *East Europe: A Chance to Stop HIV*, 262 SCIENCE 1964 (1993).

with a history or a woman with a culture. This is not true when she is a woman with AIDS. Nor is it true for an infant with AIDS. AIDS is not like Sickle Cell or Tay Sachs. AIDS is a disease that has caused confusion simply because it has crossed cultural, racial and gender lines. These lines isolated groups that always had known discrimination, but now one form of discrimination has mingled with another, and confusion has resulted.⁶⁸

If AIDS were a gay disease, a black or Hispanic disease, or a female disease, then perhaps there would be more direct action. There would be less confusion. The helping professions could identify with a defined group, perhaps even drawing upon sympathies often associated with various minority groups such as blacks, Hispanics, women and children, and the professionals could assemble a working solution. But AIDS is not a disease affecting such a narrowly defined class. AIDS affects a status that transcends racial, gender and age distinctions. It does, but then again it does not. It seems available to all, but the numbers point to particular minority communities as scandalously vulnerable. This creates confusion in the minds of the helpers, thus muting mobilization.

The energizing zeal of helping a particular group—especially one long associated with eleemosynary or political history—is absent when the status of AIDS cuts a broad swath across many particular groups. AIDS links rich white homosexual males with poor black heterosexual women, whom it links with adolescent white hemophiliac boys and rag-tag white, black and Hispanic men shooting drugs in an alley. Saying or doing something to help all of “them” confuses the best intentioned people who always have helped this or that particular group. Saying or doing something to help this “status” of AIDS does not seem to elicit the same zeal and response as when a call goes out to help a particular group. If this is so, then a marked shift in attitude must take place immediately. Those persons organizing and coordinating efforts to assist each of the particular groups of blacks, Hispanics, women, children and those who are socio-economically depressed, *must* cease thinking of AIDS as a status affecting many diverse groups and start thinking of AIDS as identified with *their* own group. There is sufficient evidence to indicate that AIDS is rapaciously spreading and killing within each of

⁶⁸ For a discussion of the manner in which AIDS has impacted groups that traditionally have been the subject of discrimination, see generally, Raymond C. O'Brien, *Discrimination: The Difference With AIDS*, 6 J. CONTEMP. HEALTH L. & POL'Y 93 (1990).

the groups mentioned, and political mobilization is necessary to provide Medicare inclusion for children.

Perhaps it would be best to be silent, to hide. If an advocacy group for blacks, Hispanics, women, children, handicapped or the poor is reluctant to increase the burden of existent discrimination upon any particular group by accepting the concomitant fact that AIDS is a reality within the group, the question arises: What is the price of silence? Likewise, if an advocacy group for any of these mentioned groups hesitates to identify AIDS with his or her group, because it is true that not all members of the group are infected, or because AIDS places a sexual or drug-related stigma on the group, then the question arises: What is the price of silence? Clearly the lesson to be learned from the affliction of the homosexual community is that the AIDS disease cannot be treated as a status affecting lots of "them." Rather, a strategy involving "us" will best confront AIDS.

Certainly as the gay and lesbian community perceived AIDS as affecting "us,"⁶⁹ confusion lifted and assistance took on an organized and purposeful zeal. Today, even with the changing surveillance case definition of AIDS,⁷⁰ the proportion of men solely with histories of ho-

⁶⁹ See, e.g.,

It is not too early to see AIDS as the homosexuals' holocaust. I have come reluctantly to believe that genocide is occurring: that we are witnessing—or *not* witnessing—the systematic, planned annihilation of some by others with the avowed purpose of eradicating an undesirable portion of the population.

LARRY KRAMER, *REPORTS FROM THE HOLOCAUST: THE MAKING OF AN AIDS ACTIVIST* 263 (1989).

One of the saddest lessons I have learned from this epidemic is that the true heterosexual liberal, for some unaccountable reason, is not necessarily the gay person's friend. He or she will fight for blacks, women, Hispanics, abortion, nuclear disarmament, keeping the Jefferson library open all week. But when it comes to homosexuality, they get queasy.

Id. at 99. "[A]t this period in the history of gay men, just staying alive is a political act." *Id.* at xvii.

⁷⁰ The first surveillance case definition was in 1982. CDC, *Update on Acquired Immune Deficiency Syndrome (AIDS)*, 31 MORBIDITY & MORTALITY WKLY. REP. 507-8, 513-14 (1982). Then in 1983, the definition was revised, Richard Selik et al., *Acquired Immune Deficiency Syndrome (AIDS) Trends in the United States, 1978-82*, 76 AM. MED. J. 493-500 (1984); then in 1985: CDC, *Revision of the Case Definition of Acquired Immunodeficiency Syndrome for National Reporting—United States*, 34 MORBIDITY & MORTALITY WKLY. REP. 373-74 (1985); and then in 1987: CDC, *Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome*, 36 MORBIDITY & MORTALITY WKLY. REP. (Supp. No. S-1 1987). This 1987 revised definition increased the number of reported cases of AIDS, especially among minorities: "A higher proportion of patients meeting only the 1987 case definition compared with those meeting the 1985 case definition were female, black or Hispanic, and/or had a history of IV-drug

homosexual or bisexual activity who are diagnosed with AIDS actually is decreasing⁷¹ in the United States: from seventy percent in 1987 to sixty-three percent in 1988.⁷² "Evidence also indicates an appreciable decline in the incidence of new infections in homosexual men,"⁷³ to the point that *The New York Times* reports, "Data over the last two years suggest that the rate at which gay men get AIDS has finally begun to flatten out at a level somewhat above 7,000 new cases a year."⁷⁴ Perhaps education complemented community support, and this brought about a change in behavior and concomitant benefits.

But changes in numbers of infected gay men, the first minority afflicted with AIDS, do not reveal the entire story. First, numbers are biased and often misleading. Are newly discovered medical treatments suppressing the numbers of persons defined as having AIDS, even

use." CDC, *AIDS and the Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 4 (Supp. No. S-4 1989). As of January 1, 1993, the new case definition for HIV classification incorporates the CD4 count and retains the 23 clinical conditions incorporated into the 1987 classification. CDC, *1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults*, 41 MORBIDITY & MORTALITY WKLY. REP. RR-17 (1992).

⁷¹ CDC, *Update: Acquired Immunodeficiency Syndrome—United States 1981-1988*, 38 MORBIDITY & MORTALITY WKLY. REP. 230, 230 (1989). However, the 1987 revisions of the case surveillance definition, may result in a 22% increase in the number of cases among homosexual men. Michael Kirn et al., *Revised Center [sic] for Disease Control AIDS Case Definition: Impact on Case Reporting [Abstract]*, IV INTERNATIONAL CONFERENCE ON AIDS, BOOK 2, STOCKHOLM, 12, 16 (1988). Thus, even though the proportion of homosexual men defined as persons with AIDS is declining, the actual number of cases still increases.

⁷² *Id.* at 2. Note that the proportional decrease does not mean there are no new cases among homosexual/bisexual men, rather only that in proportion to other groups identified by CDC, the number is decreasing. Nonetheless, the overall rate of increase of new cases has declined yearly, except in 1987, when the revised case definition resulted in an unusual increase. *Id.* Another sharp increase should follow the revised case definition in 1993, but the pattern of decline should continue among homosexual/bisexual men.

⁷³ CDC, *AIDS and the Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 12 (Supp. No. S-4 1989). For the argument that this decline is partly due to education and counseling, see Marshall H. Becker & Jill G. Joseph, *AIDS and Behavioral Change to Reduce Risk: A Review*, 78 AM. J. OF PUB. HEALTH 394-395 (1988). See generally Peter Aggleton et al., *Risking Everything? Risk Behavior, Behavior Change, and AIDS*, 265 SCIENCE 341, 345 (1994); Don Des Jarlais et al., *Continuity and Change Within an HIV Epidemic*, 271 JAMA 121 (1994); George Lemp et al., *Seroprevalence of HIV and Risk Behaviors Among Young Homosexual and Bisexual Men*, 272 JAMA 449 (1994).

⁷⁴ Lawrence K. Altman, *Who's Stricken and How: AIDS Pattern is Shifting*, N.Y. TIMES, Feb. 5, 1989, at A1. Dr. Peter Kerndt, who directs the AIDS epidemiology program for the Los Angeles Health Department, did not concur in the decline, saying the lull was due to under-reporting. *Id.* at 28. Among homosexual and bisexual men aged 17 to 22 years who frequented "public venues" in San Francisco and Berkeley in 1992 and 1993, nearly one in ten interviewed was seropositive, indicating that many were infected long after information about AIDS was widely disseminated. See Lemp, *supra* note 73, at 451.

though they are demonstrating HIV-related conditions? Because far more persons have HIV infection and related symptoms, is it appropriate to use AIDS numbers at all?⁷⁵ The answer is no.

Many HIV-infected persons suffer from illnesses that are not reportable as AIDS even under the current case definition (e.g., pneumonia in seropositive IV-drug users), and some infected persons may not have access to adequate medical or diagnostic care. Thus, the number of persons with severe HIV-related morbidity exceeds the number of diagnosed AIDS cases; reported AIDS cases may represent fewer than 80% of all cases of recognized or unrecognized severe morbidity associated with AIDS infection.⁷⁶

And then, what is the level of under-reporting? Numbers pertaining to homosexual men result from surveys taken in urban areas, but there is no data concerning increases or decreases in rural areas.

The more important aspect of the gay and lesbian community's acceptance of AIDS is mobilization. Once this minority population accepted that they were targeted for AIDS infection, an attitude developed that said "us" rather than "them," and the particular zeal of that community established health clinics, buddy programs, lobbying efforts, mailings and money. A spirit developed that is perhaps best captured in the quilt taken from coast-to-coast. Ignored was the reality that all gay and lesbian persons are not infected. Accepted was the reality that the possibility of increased discrimination was better than silence. Regardless of the reported numbers for HIV-infection or AIDS, the mobiliza-

⁷⁵ Focusing on AIDS can be misleading as this term—and ARC—refer to clinical manifestations in accordance with strict definitions, and this contributes to lack of understanding of the importance of HIV infection as the more significant element for taking control of the epidemic. This HIV infection results in many symptoms, only some of which are listed as AIDS. Thus, in its Executive Summary, the Presidential Commission wrote:

The term "AIDS" is obsolete. "HIV infection" more correctly defines the problem. The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease (ARC and AIDS). Continual focus on AIDS rather than on the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic. Federal and state data collection efforts must now be focused on early HIV reports, while still collecting data on symptomatic disease.

REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC at XVII (June 24, 1988) (PRESIDENTIAL COMMISSION).

⁷⁶ CDC, *AIDS and the Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 4 (Supp. No. S-4 1989). For more recent data indicating this conclusion, see Andrew Avins et al., *HIV Infection and Risk Behaviors Among Heterosexuals in Alcohol Treatment Programs*, 271 JAMA 515, 516 (1994); Marsha Goldsmith, "Invisible" Epidemic Now Becoming Visible as HIV/AIDS Pandemic Reaches Adolescents, 270 JAMA 16, 16 (1994); Richard Selik et al., *HIV Infection as Leading Cause of Death Among Young Adults in US Cities and States*, 269 JAMA 2991, 2994 (1993).

tion resulting from the reality of the situation is having a profound effect on persons within the gay and lesbian minority.

Current statistics reflecting who is infected with AIDS, where the infected persons live, why the infections occurred and what treatments are available should serve as clarion calls to the other minority communities, the socio-economically depressed, African-Americans and Hispanics. Particularly those concerned about the children within these groups should heed this call. The message is that AIDS is particularly targeting each of those communities. The message must be interpreted in the same manner that the gay and lesbian community did: a call to mobilization. This mobilization must address the most vulnerable of all, the children.

For the African-American community, the 1988 Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic has had the same impact as did the 1968 President's National Advisory Commission on Civil Disorders, the Kerner Commission.⁷⁷ Indeed, the Presidential Commission Report on AIDS invited no better response than did the Kerner Commission, the latter "filed away to gather dust in the archives as America tried to forget about the riots and the troubled ghettos."⁷⁸ The Presidential Commission foretold the impact that HIV would have on the African-American community, and little has been done. Nonetheless, the conclusion of a recent report in *The New England Journal of Medicine* states:

Among Patients infected with HIV, blacks were significantly less likely than whites to have received antiretroviral therapy or PCP prophylaxis when they were first referred to an HIV clinic. This disparity suggests a need for culturally specific interventions to ensure uniform access to care, including drug therapy, and uniform standards of care.⁷⁹

⁷⁷ *The President's National Advisory Commission on Civil Disorders* 1 Mar. 1, 1968. (*Kerner Report*). Johnson appointed the Kerner Commission in the summer of 1967 after riots had devastated the black sections of many of America's major cities. The Report is most often remembered for concluding "Our nation is moving toward two societies, one black, one white—separate and unequal." *Id.*

⁷⁸ For a commentary on the *Kerner Report*, see QUIET RIOTS: RACE AND POVERTY IN THE UNITED STATES (Fred R. Harris & Roger W. Wilkins eds. 1988) (QUIET RIOT).

⁷⁹ Richard Moore et al., *Racial Differences in the Use of Drug Therapy for HIV Disease in an Urban Community*, 330 NEW ENG. J. MED. 763 (1994); see also Dale Hu et al., *Geographical AIDS Rates and Socio-Demographic Variables in the Newark, New Jersey Metropolitan Area*, 9 AIDS & PUB. POL'Y J. 20 (1994).

So too must the Hispanic community, the largest minority group in the United States, read into the Presidential Commission Report the same call to mobilization. AIDS is an issue that affects each of these communities so deeply that the response must mirror the mobilization by the gay and lesbian community. Confusion over whether this is a disease affecting "us" causes the hesitation in mobilizing to protect even the most vulnerable of members: children.

The scandal of AIDS is that the numbers clearly show where the disease is and where the disease is going, and yet little is said or done. Silence. National newspapers such as *The Washington Post* have announced to all the world: "AIDS Shifting to Drug-Plagued Inner Cities."⁸⁰ This is the scandal of particularity. But little is being done to mobilize all women and men to provide support and assistance. The point should be to spark an effort at mobilization on the same scale as that in the gay and lesbian community. This will provide the community energy to place people in the streets to change what is happening. That mobilization will come about because *each* of the group—and those responsible to each group—will accept the fact that AIDS is a particular threat to "us."

But mobilization is not occurring in a manner necessary to address the problem. This is because discrimination has resulted in confusion, and confusion has made women and men impotent. Within the spirit of the Presidential Commission Report,⁸¹ all persons must address discrimination if the particular groups most affected by AIDS are to mobilize effectively. Federal and state legislators must address the reality that discrimination continues to thwart access to health care, employ-

⁸⁰ Susan Okie, *AIDS Shifts to Drug-Plagued Inner Cities*, WASH. POST, Aug. 27, 1989, at A3. Estimates are that about "1.2 million people carry the virus and that more than half of those are black or Hispanic." *Id.* For example, a recent study in San Francisco and Berkeley among homosexual and bisexual men found that one in ten was seropositive, and this is "significantly higher among young African-American homosexual and bisexual men than among men from other racial/ethnic backgrounds." Lemp, *supra* note 73, at 453. See also Hu, *supra* note 79, at 20-24; Sten Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034-35 (1993).

⁸¹ The PRESIDENTIAL COMMISSION conducted 40 hearings and listened to testimony from over 600 persons. See testimony by AIDS activist Larry Kramer. KRAMER, *supra* note 69, at 182-85. The Commission Report calls attention to the fact that, "addressing discrimination is the first critical step in the nation's response to the epidemic." PRESIDENTIAL COMMISSION, *supra* note 75, at 119. Specifically, legal and ethical issues related to discrimination are discussed. See PRESIDENTIAL COMMISSION, *supra* note 75, at 119-40.

ment, housing, education, health insurance and even funeral services.⁸² If the health care aspects of the disease are to be addressed, then the legislatures must address the social effects.

Ultimately, the discrimination must be addressed in the allocation of drugs, health care costs and education. Minorities are being infected rapidly with a host of HIV-related symptoms or compromising conditions: measles, tuberculosis, syphilis, genital ulcers and gonorrhea. At the same time, poverty, ghettoization and drugs continue unabated. What is the level of irresponsibility in regards to AIDS when the 1989 Surgeon General's Report finds that "[s]moking is responsible for more than one of every six deaths in the United States,"⁸³ and yet cigarette companies are allowed to increasingly target their marketing efforts at blacks, Hispanics and children?⁸⁴ The scandal lies in each group's reluctance to admit that AIDS affects "us" now and mobilize to address it. The scandal also lies in the nation's failure to address discrimination, and then to act responsibly. At this point in the epidemic, responsibility includes more people in the streets of these minority communities, access to health care, devising a cost-effective approach to financing treatment and finding a cure.⁸⁵ Responsibility includes the

⁸² See, e.g., *Kerins v. Hartley*, 33 Cal. Rptr. 2d 172 (Ct. App. 1994) (court discusses the fear of AIDS and alleged discrimination); *United States v. Jack H. Castle, DDS, Inc.*, 2 Health L. Rep. 1370 (BNA) (D.C. Tex. 1994) (dentist ordered to pay damages and penalties for refusing to treat a patient who revealed he was HIV-positive). See generally Bernard M. Dickens, *Legal Rights and Duties in the AIDS Epidemic*, 239 SCIENCE 580 (1988); Leon Eisenberg, *The Genesis of Fear: AIDS and the Public's Response to Science*, 14 LAW MED. HEALTH CARE 243-49 (1986); June E. Osborn, *AIDS: Politics and Science*, 318 NEW ENG. J. MED. 444-47 (1988).

⁸³ CDC, *The Surgeon General's 1989 Report on Reducing the Health Consequences of Smoking: 25 Years of Progress [Executive Summary]*, 38 MORBIDITY & MORTALITY WKLY. REP. 8 (Supp. No. S-2 1989); see also CDC, *Cigarette Smoking Among Adults—United States, 1992, and Changes in the Definition of Current Cigarette Smoking*, 43 MORBIDITY & MORTALITY WKLY. REP. 342-46 (1994); CDC, *Surveillance for Smoking-Attributable Mortality and Years of Potential Life Lost, by State—United States, 1990*, 43 MORBIDITY & MORTALITY WKLY. REP. (Supp. No. S-1 1994); CDC, *Preventing Tobacco Use Among Young People: A Report of the Surgeon General [Executive Summary]*, RR-4 (1994); CDC, *Smoking Cessation During Previous Year Among Adults—United States*, 42 MORBIDITY & MORTALITY WKLY. REP. 504-07 (1993); CDC, *Mortality Trends for Selected Smoking-Related Cancers and Breast Cancer—United States, 1950-1990*, 42 MORBIDITY & MORTALITY WKLY. REP. 857, 867 (1993).

⁸⁴ CDC, *The Surgeon General's 1989 Report on Reducing the Health Consequences of Smoking: 25 Years of Progress [Executive Summary]*, 38 MORBIDITY & MORTALITY WKLY. REP. XII (Supp. No. S-2 1989).

⁸⁵ There have been consistent efforts made to educate and transform behavior. See, e.g., *An Urgent Message to the President of the United States*, WASH. POST, Sept. 12, 1989, at A9 (prominent physicians, researchers and health care administrators signed an open letter to the President urging action). More recently, CDC, *Addressing Emerging Infectious Disease Threats: A Prevention Strategy for the United States*, 43 (RR-4) MORBIDITY & MORTALITY WKLY. REP. (1994);

recommendations of the nation's report card on HIV and the Report of the Presidential Commission on the HIV Epidemic in the United States.

Women with AIDS must be made to shed the confusion resulting from discrimination. The fact that the women affected are mostly of color but of divergent ethnic backgrounds contributes to confusion, but this also should add impetus to understanding that if they and their infants are to benefit from any health care reform, any prophylactic treatment protocols, any benefits in housing, food or respect, mobilization is the answer. And mobilization will result from the avoidance of confusion and the acceptance that this cataclysm of AIDS is a reality. It is a reality that demands the type of health care that Medicare can provide.

III. RACISM

All the data reflects the conclusion that HIV-infection among African-Americans and Hispanics is boundless. A paragraph from a publication of the Institute of Medicine/National Academy of Science graphically summarizes:

AIDS cases occur in higher proportions in black and Hispanic populations (on the West Coast, the proportion is 3 times higher in black and Hispanic than in white populations and 12 times higher on the East Coast), mainly as a result of higher HIV prevalence in black and Hispanic drug abusers and their sexual partners and offspring. Recent data also suggests that the virus is spreading more rapidly among blacks and Hispanics at risk than among other population groups, especially in Northeastern cities, suggesting that the future composition of AIDS cases will consist primarily of poor, urban minorities.⁸⁸

CDC, *Health-Risk Behaviors Among Persons Aged 12-21 Years—United States, 1992*, 43 MORBIDITY & MORTALITY WKLY. REP. 231-35 (1994); Richard Selik et al., *HIV Infection as Leading Cause of Death Among Young Adults in US Cities and States*, 269 JAMA 2991-94 (1993).

⁸⁸ INSTITUTE OF MEDICINE/NATIONAL ACADEMY OF SCIENCES, *CONFRONTING AIDS* 52 (1989) (CONFRONTING AIDS). HIV death rates vary substantially by race/ethnicity: for men aged 25 to 44 years, rates for black, Hispanic, American Indian/Alaskan Native and Asian/Pacific Islander men were approximately three times, twice, one third and one fourth, respectively, the rate for white men. CDC, *Update: Mortality Attributable to HIV Infection/AIDS Among Persons Aged 25-44 Years—United States, 1990 and 1991*, 42 MORBIDITY & MORTALITY WKLY. REP. 481, 481 (1993). Among child-bearing women, the racial factor is significant. The annual number of women aged 20 to 29 years with heterosexually acquired AIDS increased by 96.7% since 1988. "This trend primarily reflects a larger increase among non-Hispanic black women than among non-Hispanic whites and Hispanic women." CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 547, 550 (1993).

It is not that being black or Hispanic makes a person more likely to become infected. There is no proof that AIDS infects blacks in the same biological way as does Sickle Cell.⁸⁷ It is one of the scandalous unanswered questions⁸⁸ of AIDS as to why there is such a racial disproportion among persons who are HIV-positive. "The higher rate of IV-drug use among black and Hispanic groups, with consequent greater risk of HIV exposure, is clearly a contributing factor. However, this may not be the only factor since even among IV-drug users [whites as well as blacks], the HIV antibody prevalence is racially disproportionate."⁸⁹ Still, present thinking is that the higher incidence results from behavior that involves inordinate use of needle-sharing drugs,⁹⁰ or from ignorance of risk,⁹¹ rather than biology. Of course, poverty is always an ingredient because this affects diet, health care and options. The CDC has made this connection among poverty, behavior and HIV:

Because race and ethnicity are likely risk markers and not risk factors for HIV infection, these markers may assist in identifying groups at highest risk for HIV infection and targeting prevention efforts. The higher incidence of AIDS among non-Hispanic blacks and Hispanics than among non-Hispanic

⁸⁷ Note that in a study done concerning the disproportional share of plague cases among American Indians, the high incidence of plague was found to be a regional problem and not a racial one. CDC, *Reports on Selected Racial/Ethnic Groups*, 37 MORBIDITY & MORTALITY WKLY. REP. 15 (Supp. No. S-3 1988).

⁸⁸ Five thousand doctors at a national conference for black physicians called for more research into the factors that put blacks at higher risk than whites of getting AIDS. See *Black Doctors Call for Research Into Risk Factors*, WASH. BLADE, Jul. 28, 1989, at A13. While no organized study had been concluded, race as a risk marker is being considered. See, e.g., CDC, *Use of Race and Ethnicity in Public Health Surveillance: Summary of the CDC/ATSDR Workshop*, 42 MORBIDITY & MORTALITY WKLY. REP. RR-10 (1993).

⁸⁹ CDC, *Human Immunodeficiency Virus Infection in the United States: A Review of Current Knowledge*, 36 MORBIDITY & MORTALITY WKLY. REP. 11 (Supp. No. S-2 1987). This finding is reported in more recent studies as well. See, e.g., CDC, *AIDS and Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WKLY. REP. 11 (Supp. S-4 1989); Richard Moore et al., *Racial Differences in the Use of Drug Therapy for HIV Disease in an Urban Community*, 330 NEW ENG. J. MED. 763-68 (1994); Richard Selik et al., *HIV Infection as Leading Cause of Death Among Young Adults in US Cities and States*, 269 JAMA 2991-94 (1993) (deaths from AIDS in 1990 ranged from 14% to 70% depending on the sex and racial/ethnic group).

⁹⁰ Samuel R. Friedman et al., *The AIDS Epidemic Among Blacks and Hispanics*, 65 MILBANK Q. 455, 456 (Supp. No. S-2 1987); U.S. CONG. HOUSE OF REP., SELECT COMM. ON NAR. ABUSE AND CONTROL, *INTRAVENOUS DRUG USE AND AIDS: THE IMPACT ON THE BLACK COMMUNITY*, 1, 85 (1988).

⁹¹ Ralph J. DiClemente et al., *Minorities and AIDS: Knowledge, Attitudes, and Misconceptions Among Black and Latino Adolescents*, 78 AM. J. OF PUB. HEALTH 55-57 (1988); Lemp, *supra* note 73, at 453 (citing lack of peer support, feelings of invulnerability, and conviction that HIV is restricted to older men); Laura B. Randolph, *The Hidden Fear: Black Women, Bisexuals and the AIDS Risk*, EBONY, Jan. 1988, at 120.

whites probably reflects a combination of such risk factors, including socioeconomic status and access to medical care.⁹³

As the face of AIDS changes from the white middle class homosexual male to the poor woman of color, the possibility of racism exists.⁹³ Especially with infants with AIDS, "racial or ethnic bias may . . . play a role."⁹⁴ "Of the perinatally infected children in the United States, 84% are either African-American or Hispanic. By contrast, African-American and Hispanic children together comprise only 10% of the general pediatric population."⁹⁵ Based in part on surveys conducted after the death of "Baby Doe," an Indiana infant with Down syndrome who died of starvation six days after his parents refused consent to surgery to correct an obstruction of his digestive tract,⁹⁶ evidence suggests that racial bias exists in medical practice.⁹⁷ The point is that, because "most infected infants are either African-American or Latino, poor, and born into families racked by intravenous drug use, . . . an infected infant's life [is] particularly vulnerable to devaluation."⁹⁸

Racism is bolstered not only by the risk marker of HIV so prevalent in the African-American community, but also by the disproportional numbers of other diseases infecting the black and Hispanic communities. These, like HIV, are biological factors and are not the same as an innate condition. Rather, a biological factor certainly facilitates HIV and is the direct result of behavior.⁹⁹ These other diseases are

⁹³ CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 547, 551 (1993); see also CDC, *AIDS Among Racial/Ethnic Minorities—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 644, 655 (1994).

⁹⁴ This is not to say that discrimination does not exist with the white middle class homosexual male, nor that racism has not existed in the past in regards to both male and female persons of color. See generally Raymond C. O'Brien, *Discrimination: The Difference With AIDS*, 6 J. CONTEMP. HEALTH L. & POL'Y 93 (1990).

⁹⁵ Crossley, *supra* note 52, at 1602-05.

⁹⁶ *Id.* at 1603-04.

⁹⁷ See *id.* at 1605-06.

⁹⁸ *Id.* at 1604.

⁹⁹ *Id.* at 1587. It is indisputable that "there has been clear under representation of African-American HIV-infected persons in . . . landmark studies that have dramatically influenced HIV care." Wafaa El-Sadr & Linnea Capps, *The Challenge of Minority Recruitment in Clinical Trials for AIDS*, 267 JAMA 954, 955 (1992).

⁹⁹ Note that behavior can change through education. The number of sexually transmitted diseases—as well as the proportion of AIDS cases—are decreasing in the homosexual community. See CDC, *AIDS and Human Immunodeficiency Virus Infection in the United States: 1988 Update*, 38 MORBIDITY & MORTALITY WEEKLY REPORT 12 (Supp. No. S-4 1989); Sten H. Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034 (1993) (The U.S. HIV/AIDS epidemic is now an amalgam of both upward trends from injection drug users

primarily herpes, syphilis, gonorrhea, measles, tuberculosis and pneumonia. Thus, for a health care system already burdened beyond capacity, providing care to persons associated with HIV and a host of other diseases could seem useless and even incomprehensible. Society approaches these persons not from individual rationality but from a classification based upon insurmountable obstacle. A few sentences from a recent editorial in the *Journal of the American Medical Association* summarizes this despair:

Persons living with AIDS/HIV who have low or modest incomes do not generally have good access to HIV screening, diagnosis, and preventive health care. The burden in minority communities is profound and largely unrecognized, even by practitioners seeing many HIV-infected patients. Where injection drug use and urban poverty are already prevalent [and one could add any of the diseases identified previously], HIV/AIDS has been superimposed on already high mortality rates in young adults.¹⁰⁰

There is a definite association between AIDS and the host of other diseases infecting blacks and Hispanics. "The association between use of illicit drugs and recent increases in syphilis, and between non-IV use of cocaine (e.g. 'crack') and sexual activity links illicit drug use to an increased potential for sexual HIV transmission."¹⁰¹ Drugs may bring about sex, which brings about a sexually transmitted disease, which brings about increased vulnerability to HIV infection. According to CDC reports: "If gonorrhea and other sexually transmitted infections are cofactors for facilitating the transmission of human immunodeficiency virus (HIV), the high incidence of gonorrhea in some lo-

and heterosexuals, and downward trends for blood product recipients and male homosexuals). *But see* CDC, *Coordinated Community Programs for HIV Prevention Among Intravenous-Drug Users—California, Massachusetts*, 38 MORBIDITY & MORTALITY WKLY. REP. 369, 373 (1989) (changes in the behaviors reported by IVDUs participating in the educational programs were modest); *see also* Andrew Avins et al., *HIV Infection and Risk Behaviors Among Heterosexuals in Alcohol Treatment Programs*, 271 JAMA 515 (1994).

¹⁰⁰ Sten H. Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034, 3035 (1993).

¹⁰¹ CDC, *Update: Acquired Immunodeficiency Syndrome Associated With Intravenous-Drug Use—United States, 1988*, 38 MORBIDITY & MORTALITY WKLY. REP. 165, 170 (1989); Michael H. Merson, *Slowing the Spread of HIV: Agenda for the 1990s*, 260 SCIENCE 1266, 1267 (1993) ("Given the enormous magnifying effect of conventional STDs on HIV transmission, effective STD care must be a priority throughout this decade and into the next century."). *See also* CDC, *Relationship of Syphilis to Drug Use and Prostitution—Connecticut and Philadelphia, Pennsylvania*, 37 MORBIDITY & MORTALITY WKLY. REP. 755-64 (1988); NATIONAL RSCH. COUN., *AIDS: SEXUAL BEHAVIOR AND INTRAVENOUS DRUG USE*, 166 (1989).

cales among some populations of adolescents could result in dramatic increases in HIV acquisition"¹⁰²

The known presence of these diseases in definite geographical area—the numbers speak for themselves—is testimony to the scandal that surrounds the particular devastation in the minority groups. A clear picture results from examining certain diseases such as syphilis, tuberculosis, measles and then the particular targeting of drugs and poverty. The picture is a vector formed by the intersecting lines of these five factors. Persons within this vector are the ones in clear and present danger. That so many of these persons are African-American and Hispanic contributes to the premise that health care, distribution of services and quality of existing care may differ according to race. And furthermore, an attitude of differential treatment—especially in relationship to infants with AIDs—may result even in locations where better treatment is affordable. Race, combined with an attitude of insurmountable obstacle that has no rational basis, is racist.

Perhaps the cycle of racism and inferior care would be reduced or eliminated if Medicare were a factor. That is, if a child qualified for health care simply because he or she were a child, rather than because the child had money, insurance or lived in an area with superlative Medicaid assistance, racism may not exist. In fact, Medicare availability for children may attract health care providers to ghetto areas in the same manner that Medicare has caused greater numbers of physicians to begin treating older and sicker patients.¹⁰³ The presence of these health care providers would do much to counteract the attitude that specific disease, HIV and race combine to form an insurmountable obstacle to care.

The diseases contributing to the notion that persons affected with HIV are part of an insurmountable obstacle follow. Attention should be

¹⁰² CDC, *Special Focus: Surveillance for Sexually Transmitted Diseases*, 42 MORBIDITY & MORTALITY WKLY. REP. 1-2 (Supp. No. S-3 1993). See also CDC, *1993 Sexually Transmitted Diseases Treatment Guidelines*, 42 MORBIDITY & MORTALITY WKLY. REP. RR-14 (1993); CDC, *Summary of Notifiable Diseases, United States 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 3 (1993).

¹⁰³ See GREEN BOOK, *supra* note 10, at 137:

The rates of growth in older and sicker patients entering treatment for end stage renal disease indicate a shift in physician practice patterns. In the past, most of these people would not have entered dialysis treatment because their age and severity of illness made successful treatment for renal failure less likely [I]t is clear that these practice patterns have, and will continue, to result in steady growth in the numbers of patients enrolling in Medicare's end stage renal program. *Id.*

paid to the racial component and to the prevalence associated with urban areas that are also common locations for infants with AIDS. The point is that these diseases, taken in tandem with HIV, create an attitude of differential treatment that is racist.

A. Syphilis

It is useful to take 1987 as an example while noting the racial differences.¹⁰⁴ Through the first forty-six weeks of 1987, 31,323 cases of infectious syphilis were reported to the Centers for Disease Control.¹⁰⁵ This number exceeded that recorded during the same period in 1986 by 32%.¹⁰⁶ Eighty-three percent of the increase was reported from Florida, New York City and California. "The greatest absolute increases occurred among blacks,"¹⁰⁷ with the second largest increase among Hispanics.¹⁰⁸ "The marked increase among inner-city, heterosexual minority groups suggests that high-risk sexual activity is increasing in these groups despite the risk of HIV infection, which is already elevated because of the high prevalence of intravenous drug abuse."¹⁰⁹ A comparison among black, Hispanic and whites would show:

¹⁰⁴ More recent studies indicate that in 1990, "the percentage of syphilis cases among blacks reported from public sources was higher than the percentage of cases among whites in all regions of the United States." CDC, *Regional and Temporal Trends in the Surveillance of Syphilis, United States, 1986-1990*, 40 MORBIDITY & MORTALITY WKLY. REP. 29, 30 (Supp. No. S-3 1991); by 1991, there was a decline in both the number and rate of reported cases in every racial group in the United States and in both sexes. Linda A. Webster & Robert T. Rolfs, *Surveillance for Primary and Secondary Syphilis—United States, 1991*, 42 MORBIDITY & MORTALITY WKLY. REP. 13, 15 (Supp. No. S-3 1993). "The reasons for the decline in syphilis are unclear." *Id.* at 16. Nonetheless, "[t]he incidence of syphilis is increasing among adolescents. From 1987 through 1991, the national incidence of primary and secondary syphilis for persons aged 15-19 years increased 40%." CDC, *Syphilis—Ford County, Kansas, 1992*, 41 MORBIDITY & MORTALITY WKLY. REP. 644, 645 (1992). For rates of sexual activity among adolescents, including racial compositions, see CDC, *Sexual Behavior Among High School Students—United States, 1990*, 40 MORBIDITY & MORTALITY WKLY. REP. 885 (1992).

¹⁰⁵ CDC, *Continuing Increase in Infectious Syphilis—United States*, 37 MORBIDITY & MORTALITY WKLY. REP. 35 (1988). Nonetheless, by September 9, 1994, cumulative cases for primary and secondary syphilis totaled 14,544, compared to 17,769 for the same period in 1993. CDC, *Summary-Cases of Specified Notifiable Disease*, 43 MORBIDITY & MORTALITY WKLY. REP. 648, 650 (1994).

¹⁰⁶ CDC, *Summary-Cases of Specified Notifiable Disease*, 43 MORBIDITY & MORTALITY WKLY. REP. 648, 650 (1994).

¹⁰⁷ *Continuing Increase in Infectious Syphilis—United States*, *supra* note 105, at 37.

¹⁰⁸ *Id.*

¹⁰⁹ *Id.* at 38. Of greatest concern is the evidence that concludes persons receiving counseling after an initial contact with a sexually transmitted disease showed high rates of repeat diseases. In one clinic population, 15% of HIV-seropositive patients and 23% of seronegative patients were

TABLE 1

	NUMBER OF CASES ¹¹⁰		CHANGE
	1986	1987	%
HETEROSEXUAL MALES			
TOTAL	5,503	9,727	+77%
WHITE	647	940	+45%
BLACK	3,461	6,436	+86%
HISPANIC	1,200	1,874	+56%
FEMALES			
TOTAL	3,302	5,761	+75%
WHITE	376	629	+67%
BLACK	2,480	4,317	+74%
HISPANIC	332	580	+75%

These numbers give just one indication of the prevalence and potential of HIV-infection within a particular part of the population and in particular areas of the nation where that population lives. If syphilis comes about through sexual activity brought on in part through drug use, and syphilis makes a person more likely to become HIV-infected, then what happens after seroconversion and deficiency of the immune system?

B. Tuberculosis

In 1989, the CDC wrote, "tuberculosis case rates have progressively declined for all races over the past two decades, the decrease has been much less among nonwhites than among whites."¹¹¹ "More than

diagnosed with new STDs or STD exposure. Jonathan M. Zenilman et al., *Effect of HIV Posttest Counseling on STD Incidence*, 267 JAMA 845, 852 (1992).

¹¹⁰ While the cases do not indicate if the infected person is a minor or an adult, for purposes of targeting education, it is important to note that "rates of sexual experience (e.g., percentage having had intercourse) are higher for black teenagers than for white teenagers at every age and for both sexes." CDC, *Guidelines for Effective School Health Education to Prevent the Spread of AIDS*, 37 MORBIDITY & MORTALITY WKLY. REP. 11 (Supp. No. S-2 1988). See also for current statistics, CDC, *Health Risk Behaviors Among Persons Aged 12-21 Years—U.S., 1992*, 43 MORBIDITY & MORTALITY WKLY. REP. 231, 232 (1994); CDC, *AIDS Among Racial/Ethnic Minorities—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 644, 655 (1994).

¹¹¹ CDC, *A Strategic Plan for the Elimination of Tuberculosis in the United States*, 38 MORBIDITY & MORTALITY WKLY. REP. 2 (Supp. S-3 1989).

80% of childhood cases occur in minority groups.”¹¹² But by 1992, “[twenty-two] states reported increases over 1991 in the number of TB cases . . . [and] the largest increases occurred in Virginia (20.6%), Illinois (6.5%), New York (including New York City (3.3%), and California (2.1 %).”¹¹³ For minorities, the rise in tuberculosis rates was catastrophic. “Reported cases increased among Hispanics by 74.5 %, among Asians/Pacific Islanders by 46.2 %, and among non-Hispanic blacks by 26.8 %.”¹¹⁴

By 1992, the CDC wrote, “[a]t no time in recent history has tuberculosis (TB) been as great a concern as it is today.”¹¹⁵ “In 1984, the long-standing annual decline in TB cases abruptly ended, and from 1985 through 1991, approximately 39,000 more cases were reported than would have been expected had the previous downward trend continued.”¹¹⁶ Furthermore, the disease has targeted children and racial and ethnic minorities. “In 1990, almost 70 % of all TB cases and 86 % of those among children [less than fifteen years old] occurred among racial/ethnic minorities.”¹¹⁷ In addition, “[A] variety of evidence supports the hypothesis that the epidemic of Human Immunodeficiency Virus (HIV), the agent responsible for Acquired Immunodeficiency Virus (AIDS), is contributing substantially to this observed rise in tuberculosis cases.”¹¹⁸

¹¹² *Id.* at 3.

¹¹³ CDC, *Tuberculosis Morbidity—United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 696 (1993).

¹¹⁴ *Id.* at 697.

¹¹⁵ CDC, *National Action Plan to Combat Multidrug-Resistant Tuberculosis*, 41 MORBIDITY & MORTALITY WKLY. REP. RR-11 (1992). As an example of efforts being made to address the problem, see CDC, *Tuberculosis Control Laws—United States, 1993*, 42 MORBIDITY & MORTALITY WKLY. REP. RR-15 (1993).

¹¹⁶ *National Action Plan to Combat Multidrug-Resistant Tuberculosis*, *supra* note 115, at 6.

¹¹⁷ CDC, *Prevention and Control of Tuberculosis in U.S. Communities With At-Risk Minority Populations: Recommendations of the Advisory Council for the Elimination of Tuberculosis*, 41 MORBIDITY & MORTALITY WKLY. REP. 1 (1992). See also CDC, *Prevention and Control of Tuberculosis in Migrant Farm Workers*, 41 MORBIDITY & MORTALITY WKLY. REP. RR-10 (1992); CDC, *Tuberculosis Infection Among U.S. Residents of Cuban Descent—Dade County, Florida, 1982-1984*, 41 MORBIDITY & MORTALITY WKLY. REP. 74 (1992).

¹¹⁸ John A. Jareb et al., *Tuberculosis Morbidity in the United States: Final Data, 1990*, 40 MORBIDITY & MORTALITY WKLY. REP. 23, 24 (1991). See also Samuel W. Dooley et al., *Nosocomial Transmission of Tuberculosis in a Hospital Unit for HIV-Infected Patients*, 267 JAMA 2632 (1992); Brian R. Edlin et al., *An Outbreak of Multi-Drug Resistant Tuberculosis Among Hospitalized Patients with the Acquired Immunodeficiency Syndrome*, 326 NEW ENG. J. MED. 1514 (1992); Peter A. Selwyn et al., *High Risk of Active Tuberculosis in HIV-Infected Drug Users With Cutaneous Anergy*, 268 JAMA 504 (1992).

Tuberculosis is a higher risk for minorities because lower socioeconomic conditions affect more minorities. "[T]uberculosis (TB) and other mycobacterioses are well-recognized complications of immunosuppression."¹¹⁹ Thus, the number of tuberculosis cases and the actual presence or potential presence of HIV infection cannot be minimized because "evidence for an association between HIV infection and TB comes from several studies."¹²⁰ Tuberculosis is a definite indication of the presence of HIV infection.¹²¹

Sufficient information exists to posit that "minority populations in some areas have been at particular risk of HIV-associated TB."¹²² Neither the areas nor the minorities TB affects should be surprises. "Detailed demographic information obtained from registry matching in New York City, Florida, and Newark, New Jersey, revealed that blacks and Hispanics accounted for 80%, 90% and 100%, respectively, of the TB/AIDS cases."¹²³ This means that, particularly in these areas and generally in others, latent "tuberculosis infection may often progress to clinical TB early in the course of HIV-induced immunosuppression and that AIDS patients known to have developed TB may represent only a small proportion of total HIV-associated TB morbidity."¹²⁴ This will result in the under-reporting of AIDS statistics,

¹¹⁹ CDC, *Tuberculosis and Human Immunodeficiency Virus Infection: Recommendations of the Advisory Committee for the Elimination of Tuberculosis (ACET)*, 38 MORBIDITY & MORTALITY WKLY. REP. 236 (1989) (*ACET Recommendations*).

¹²⁰ *Id.* at 237. See P.A. Selwyn et al., *A Prospective Study of the Risk of Tuberculosis Among Intravenous Drug Users with Human Immunodeficiency Virus Infection*, 320 NEW ENG. J. MED. 545-50 (1989); see also Jean Pape et al., *Effect of Isoniazid Prophylaxis on Incidence of Active Tuberculosis and Progression of HIV Infection*, 342 LANCET 268-72 (1993); Andrew Zolopa et al., *HIV and Tuberculosis Infection in San Francisco's Homeless Adults*, 272 JAMA 455-61 (1994).

¹²¹ See Daniel G. Kirschenbaum, *Interaction With Other Infections is Becoming Clearer*, 117 NEW SCIENTIST 34 (1988) (In Africa, diseases such as TB, malaria and leprosy, which had been brought under control, are beginning to spread again, and the reason may be the AIDS virus); Aaron Glatt et al., *Treatment of Infections Associated with Human Immunodeficiency Virus*, 318 NEW ENG. J. MED. 1439, 1442-43 (1988) (Some opportunistic infections, including tuberculosis, are more common in persons with AIDS.).

¹²² *ACET Recommendations*, *supra* note 119, at 237.

¹²³ *Id.* See Gnana Sunderam et al., *Tuberculosis as a Manifestation of the Acquired Immunodeficiency Syndrome (AIDS)*, 256 JAMA 362, 363 (1986); CDC, *Tuberculosis and Acquired Immunodeficiency Syndrome—New York City*, 36 MORBIDITY & MORTALITY WKLY. REP. 785, 789 (1987); CDC, *Tuberculosis and Acquired Immunodeficiency Syndrome—Florida*, 35 MORBIDITY & MORTALITY WKLY. REP. 587 (1986).

¹²⁴ *ACET Recommendations*, *supra* note 119, at 237. This is another example of how numbers associated with AIDS are misleading. For example, persons have died of tuberculosis or other infections without having met the definition of AIDS.

thereby underestimating the extent of AIDS within localized minority groups. It is safe to conclude that many of the persons who died of tuberculosis may well have been infected with HIV.

Unlike syphilis, which demands more than a casual encounter, tuberculosis portends grave consequences for the general public—particularly children—who come into contact with TB infected persons.¹²⁵ Health care persons and persons with immunodeficiencies are particularly vulnerable to TB infection. "Failure to diagnose and manage TB appropriately can result in the death of the patient and infection of contacts, including other patients and health-care personnel."¹²⁶ But the true consequence of TB and its danger within HIV populations arises within the confines of many urban ghettos, large centers for the homeless,¹²⁷ places where poverty is endemic and the very places where AIDS is spreading most rapidly through IV-drug use. Imagine particular places of poverty in the United States where many persons are IV drug users, are HIV-infected, have tuberculosis and have syphilis—and many of them are also women and children. Minority women account for seventy percent of all female AIDS cases and minority children seventy-five percent of all pediatric AIDS-infected children.¹²⁸

¹²⁵ The increased risk of tuberculosis in HIV-seropositive patients suggests that an additional risk of the horizontal transmission of tuberculosis to household members, health care workers, and other non-intimate contacts may exist. The aggressive identification and treatment of HIV-infected intravenous drug users with latent tuberculosis infection is therefore of both clinical and public health importance.

Selwyn et al., *supra* note 120, at 549. In January 1993, an expanded surveillance system for TB was introduced, indicating an "excess of approximately 64,000 reported cases, compared with the number predicted based on the trend of decline from 1980 through 1984." CDC, *Expanded Tuberculosis Surveillance and Tuberculosis Morbidity—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 361 (1994).

¹²⁶ *Id.* at 243. "Health-care providers who administer aerosol pentamidine as prophylaxis against PCP should be aware of several occupational safety issues." CDC, *Guidelines for Prophylaxis Against Pneumocystis Carinii Pneumonia for Persons Infected With Human Immunodeficiency Virus*, 38 MORBIDITY & MORTALITY WKLY. REP. 8 (Supp. No. S-5 1989). If the nebulizer used to administer the drug is used improperly, infection may be spread throughout the treatment room. *Id.* Ultraviolet lights are helpful in killing airborne tubercle bacilli. ACET *Recommendations*, *supra* note 119, at 245. The ACET also joins the World Health Organization in recommending that doctors should not administer the BCG vaccination to persons with HIV infection in countries where the risk of infection is low, such as the United States. *Id.* at 248.

¹²⁷ See, e.g., A COMMON DESTINY: BLACKS AND AMERICAN SOCIETY (Gerald D. Jaynes & Robin M. Williams, Jr., eds. 1989); JONATHAN KOZOL, RACHEL AND HER CHILDREN (1988); DANIEL P. MOYNIHAN, FAMILY AND NATION (1986); LISBETH SCHORR, WITHIN OUR REACH (1988).

¹²⁸ See, e.g., CDC, *Tuberculosis Among Pregnant Women—New York City, 1985-1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 605 (1993).

As with syphilis, TB is another malady affecting a population already impacted with discrimination and racial stereotyping. Taken together, these conditions present what seems to be an insurmountable obstacle to care or treatment. This insurmountable obstacle contributes to the dilemma of selective nontreatment of infants with AIDS.

C. Measles

As with other diseases associated with AIDS, measles has declined significantly in the American population. But today there is a seesaw effect being experienced, perhaps because of AIDS. Nevertheless, this much is certain: even though the number of cases of measles declined significantly in the United States during 1993, the cases reported occurred in settings of low vaccination coverage.¹²⁹ These low vaccination areas are inner-city areas: "age-appropriate vaccination coverage efforts must be improved—particularly among preschool-aged children living in inner-city areas. Transmission of measles among preschool-aged children is likely to recur unless measles vaccine coverage is improved and age-appropriate vaccination is ensured."¹³⁰

"Since measles vaccine was licensed in 1963, the incidence of measles has declined to approximately 1%-2% of that reported in the prevaccine era."¹³¹ However, "increases in the number of reported cases have occurred annually since the record low in 1983, when 1497 cases were reported. There were more cases in 1986 than in any year since 1980, when 13,506 cases were reported."¹³² And measles is especially tragic because forty percent of all cases occur among preschool-aged children. However, by 1987, there was a forty-two percent de-

¹²⁹ See CDC, *Measles—United States, First 26 Weeks, 1993*, 42 MORBIDITY & MORTALITY WKLY. REP. 813 (1993).

¹³⁰ CDC, *Measles—United States, 1992*, 42 MORBIDITY & MORTALITY WKLY. REP. 378, 380 (1993). See also CDC, *Retrospective Assessment of Vaccination Coverage Among School-Aged Children—Selected U.S. Cities, 1991*, 41 MORBIDITY & MORTALITY WKLY. REP. 103 (1992).

¹³¹ CDC, *Measles Surveillance Report No. 11, 1977-1981*, U.S. Dept. of Health & Human Serv., Public Health Serv. (1982).

¹³² CDC, *Measles—United States, 1986*, 36 MORBIDITY & MORTALITY WKLY. REP. 303 (1987). The numbers continue to vacillate between high and low. For instance, "as of July 2, 1994 (week 26), local and state health departments in 31 states had reported a provisional total of 730 measles cases to CDC for 1994, . . . a fourfold increase over the historic low of 167 cases . . . during the same period in 1993." CDC, *Measles—United States, First 26 Weeks, 1994*, 43 MORBIDITY & MORTALITY WKLY. REP. 673, 673 (1994).

crease in the number of cases, and the World Health Organization¹³³ and the United States Immunization Practices Advisory Committee (ACIP) recommended that doctors consider the measles vaccine for symptomatic as well as asymptomatic children with HIV infection.¹³⁴

In spite of immunization, CDC reported 4848 measles cases on May 27, 1989, compared with 1273 cases on May 28, 1988.¹³⁵ An urban area with a large minority population, Washington, D.C., recently reported through *The Washington Post* that: "Washington area health officials yesterday reported the largest outbreak of measles in local pre-school children in [ten] years and urged parents to immunize their youngsters against the highly contagious and potentially fatal disease."¹³⁶ Similarly, affected urban areas are also areas of AIDS concentration. For instance, "There have been 8,000 cases of measles reported this year nationwide . . . Los Angeles, Houston and Newark have experienced similar upswings recently among children younger than 5."¹³⁷

Most persons would suspect that vaccination would prevent the disease, but this is not the case: "A large proportion of persons who acquired measles had been vaccinated."¹³⁸ Failure of the vaccination is

¹³³ Global Adv. Group, Who, *Expanded Programme on Immunization*, 62 WEEKLY EPIDEMIC REC. 5, 9 (1987) (The World Health Organization recommends providing measles vaccinations for all children in developing countries, regardless of HIV and symptom status because of the high risk of measles and the severity of measles infection in general.).

¹³⁴ CDC, *Immunization Practices Advisory Committee. Immunization of Children Infected with Human Immunodeficiency Virus—Supplementary ACIP Statement*, 37 MORBIDITY & MORTALITY WKLY. REP. 181 (1988).

¹³⁵ CDC, *Summary—Cases of Specified Notifiable Diseases, United States*, 38 MORBIDITY & MORTALITY WKLY. REP. 374 (1989). Current statistics indicate an increase. See CDC, *Measles—United States, First 26 Weeks, 1994*, 43 MORBIDITY & MORTALITY WKLY. REP. 673, 673 (1994).

¹³⁶ Dana Priest, *Measles Outbreak Here Prompts Calls to Immunize Youngsters*, WASH. POST, Aug. 17, 1989, at B1. Many children are not vaccinated. See CDC, *Assessment of Undervaccinated Children Following a Mass Vaccination Campaign—Kansas, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 572, 573 (1994).

¹³⁷ Priest, *supra* note 136, at B1.

¹³⁸ CDC, *Measles—United States, First 26 Weeks, 1987*, 37 MORBIDITY & MORTALITY WKLY. REP. 56 (1988). During 1987, 47.5% of the patients had been vaccinated on or after the first birthday, and 47.9% were unvaccinated. CDC, *Measles—United States, 1987*, 37 MORBIDITY & MORTALITY WKLY. REP. 527, 528 (1988). Because studies have demonstrated persons vaccinated at 12 to 14 months of age to be at slightly higher risk for measles than persons vaccinated at 15 months or more of age, the Immunization Practices Advisory Committee recommended that persons previously vaccinated at twelve to fourteen months of age be re-vaccinated. *Measles—United States, First 26 Weeks, 1987*, at 526. See also CDC, *Impact of Missed Opportunities to Vaccinate Preschool-Aged Children on Vaccination Coverage Levels—Selected U.S. Sites*,

probably due to the age at which the vaccination took place or failure to seroconvert following vaccination. Then too, many persons within the inner-city areas, most of them minorities, never have received vaccinations, even though current thinking is that all children should be vaccinated, regardless of HIV status.¹³⁹ Data from the National Center for Health Statistics demonstrates the low level of immunization, especially for nonwhite children:

TABLE 2
IMMUNIZATION OF CHILDREN [IN PERCENTAGES]¹⁴⁰

	MEASLES		MUMPS		POLIO	
	1976	1985	1976	1985	1976	1985
WHITE	68.3	63.6	50.3	61.8	66.2	58.9
NONWHITE	54.8	48.8	61.8	47.0	39.9	40.1

This low level of immunization is especially dangerous to children within the context of inner-city, lowest socioeconomic, HIV-most-prevalent, geographical areas.

During 1986 and 1987, large measles outbreaks occurred in urban areas of the United States among preschool-age children with low immunization levels. These areas (New York City, Jersey City, and Miami) also have high incidence rates of pediatric acquired immunodeficiency syndrome. Since HIV-infected children live in areas where measles virus circulates because of low preschool measles immunization levels, they (HIV-infected children) may be at higher risk of exposure to measles than other children in the United States.¹⁴¹

Even as long ago as 1986, this geographical trend was evident: New Jersey had the highest incidence rate in preschoolers, followed by

1991-1992, 43 MORBIDITY & MORTALITY WKLY. REP. 709, 718 (1994); Orenstein et al., *Appropriate Age for Measles Vaccination in the United States*, 65 DEV. BIOL. STANDARDS 13, 21 (1986); *Immunization of Children Infected With Human Immunodeficiency Virus*, *supra* note 134, at 181-83.

¹³⁹ The risks from disease are much greater than risks associated with the vaccines; therefore, vaccination is recommended. See *Immunization of Children Infected with Human Immunodeficiency Virus*, *supra* note 134, at 181-86.

¹⁴⁰ Reprinted in _____, _____, COMMON DESTINY, *supra* note 127, at _____. See also CDC, *Vaccination Coverage of 2-Year-Old Children—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 705, 709 (1994) (up to 2 million children remain in need of one or more of the necessary doses).

¹⁴¹ CDC, *Measles in HIV-Infected Children, United States*, 37 MORBIDITY & MORTALITY WKLY. REP. 183, 185 (1988).

New York, Illinois, Florida and Arizona.¹⁴² It seems safe to conclude that certain inner-city areas are disease-settings in which measles—and tuberculosis—may spawn and thrive among preschool-age children. The geography is even more dramatic when the horror of homeless children is envisioned in the inner-cities.¹⁴³

And more of these children are dying. During 1986-87, the CDC received reports of six cases of measles that occurred among HIV-infected children. Two of these children died from measles, and, as with other infections, measles appears to be more severe in persons with HIV infection.¹⁴⁴ None of these children had been vaccinated and probably were exposed to measles from persons who had come into contact with HIV-infected patients.¹⁴⁵ While there may be under-reporting of non-hospitalized or nonfatal measles cases in persons with HIV infection,¹⁴⁶ the case-fatality rate for measles in HIV-infected children is clearly higher than the overall case-fatality rate for measles in the United States in recent years.¹⁴⁷

Measles continues to be a seesaw of reporting statistics. Nonetheless, this only means that continued surveillance will verify or reject the hypothesis that measles is another definite sign that AIDS is affecting the African-American and Hispanic communities in a particularly deadly fashion.

Also the point is *not* to emphasize numbers or statistics in a manner that will draw attention to the horror of syphilis, tuberculosis or measles. Rather, the point is to demonstrate that the numbers offer

¹⁴² CDC, *Measles—United States*, 36 MORBIDITY & MORTALITY WKLY. REP. 302 (1987). See also CDC, *Reported Vaccine-Preventable Diseases—United States, 1993, and the Childhood Immunization Initiative*, 43 MORBIDITY & MORTALITY WKLY. REP. 57 (1994).

¹⁴³ See, e.g., ALEX KOTLOWITZ, *THERE ARE NO CHILDREN HERE* (1991); KOZOL, *supra* note 127; JAMES T. PATTERSON, *AMERICA'S STRUGGLE AGAINST POVERTY 1900-1980* (1981); SCHORR, *supra* note 127.

¹⁴⁴ *Measles in HIV-Infected Children*, *supra* note 141, at 183.

¹⁴⁵ *Id.* at 183-84.

¹⁴⁶ This under-reporting is especially likely in lower socioeconomic areas, often populated with blacks and Hispanics. This is true because of the cost of medical care access to that care, and possible discrimination. "Blacks are twice as likely as whites to be without a regular source of medical care or to have no regular source other than a hospital outpatient department or emergency room." COMMON DESTINY, *supra* note 127, at 431. "The use of medical care by children has been found to be highly sensitive to the cost of obtaining care. The Medicaid program offers care for many of the very poorest children but typically in settings that make access more burdensome for Medicaid children and serve to reduce access." *Id.* at 439. "Poverty limits access to medical care." *Id.*

¹⁴⁷ *Measles Surveillance Report No. 11, 1977-81*, *supra* note 131.

clear and convincing evidence that AIDS is targeting a particular part of the population. The incidence of measles, like that of tuberculosis and syphilis, offers clear and convincing evidence that something is taking place in certain geographical areas that happen to be populated with African-American and Hispanic persons. This something is AIDS, and the implications are alarming. For women and their children and for infants with AIDS, the numbers add to the perception that this situation is an insurmountable obstacle, thus justifying selective nontreatment.

D. Drugs

Once again, the use of drugs is not confined to African-American or Hispanic persons, but when placed within the context of AIDS, "Black and Hispanic men with AIDS were more likely to have had histories of IV-drug use and less likely to have had histories of homosexual activity than white men."¹⁴⁸ Thus, in areas where there is significant drug trafficking, this factor is likely to transform black and Hispanic men and women and their children, into persons with AIDS. The stigma results because this is another factor—like syphilis, tuberculosis and measles—that contributes to the attitude of an insurmountable obstacle.

The true dimensions of drug use for blacks may be under reported. This hypothesis is supported by a 1979 survey that found mortality from drug-related deaths increased steeply in nine major metropolitan areas, and about one-third of those fatalities occurred among black youth in the 15-24 age group.¹⁴⁹

A recently completed household survey sponsored by the National Institute on Drug Abuse reports that there is no significant difference in drug use among blacks and whites, but there is a sharp increase in

¹⁴⁸ CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1981-1988*, 38 MORBIDITY & MORTALITY WKLY. REP. 232 (1989). "Black and Hispanic women with AIDS were more likely than white women to have had histories of IV-drug use or histories of sex with IVDUs." *Id.* See also CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1992*, 270 JAMA 932 (1993); CDC, *Distribution of STD Clinic Patients Along a Stages-of-Behavioral-Change Continuum—Selected Sites, 1993*, 270 JAMA 2671 (1993); CDC, *Self-Reported HIV-Antibody Testing Among Persons With Selected Risk Behaviors—Southern Los Angeles County, 1991-1992*, 270 JAMA 2033 (1993); Hu *supra* note 79, at 20; Selik et al., *supra* note 47, at 2991-94.

¹⁴⁹ COMMON DESTINY, *supra* note 127, at 414 (quoting U.S. DEPT. OF HEALTH & HUMAN SERV., RESEARCH MONOGRAPH, DRUG ABUSE DEATHS IN NINE CITIES: A SURVEY REPORT, (1980)).

cocaine use among Hispanics.¹⁵⁰ However, the same study also concluded that cocaine addiction has grown substantially, especially among the young and unemployed.¹⁵¹

So it is important to emphasize that drug use alone among minority groups is not an absolute indication of AIDS prevalence, even though the data shows that, "AIDS is more prevalent among blacks than among the general population because a larger percentage of blacks are intravenous drug users."¹⁵² There is another factor that seems to be necessary before the use of drugs may result in a particular concentration of persons who are HIV-infected. This factor is poverty or depressed socioeconomic status. More minorities are likely to be poor, and, as an article in the *New Scientist* stated, "Poverty Spreads AIDS."¹⁵³ This is the catalyst that, more than any other factor, transforms the despair of drugs into the horror of AIDS for minorities. This, and the fact that poverty is so geographically concentrated, turns urban

¹⁵⁰ Michael Isikoff, *Casual Use of Drugs Found to Drop Sharply*, WASH. POST. Aug. 1, 1989, at A1. Note that increasingly today, cocaine and other drugs are being used intravenously. "Prevention of HIV infection in IV-cocaine users is further complicated because those persons engage in more frequent injection and needle sharing than do other IVDUs and because, unlike methadone for treatment of heroin dependence, there is no specific therapy for treating cocaine dependence." Richard Chaisson et al., *Cocaine Use and HIV Infection in Intravenous Drug Users in San Francisco*, 261 JAMA 561, 565 (1989); *Update: Acquired Immunodeficiency Syndrome Associated With Intravenous-Drug Use—United States, 1988*, *supra* note 101, at 170; Stanley Weiss, *Link Between Cocaine and Retroviral Infection*, 261 JAMA 607 (1989).

¹⁵¹ Isikoff, *supra* note 150, at A1. "In poor, inner-city communities young smokers of crack cocaine, particularly women who have sex in exchange for money or drugs, are at high risk for HIV infection. Crack use promotes the heterosexual transmission of HIV." Brian R. Edlin et al., *Intersecting Epidemics—Crack Cocaine Use and HIV Infection Among Inner-City Young Adults*, 331 NEW ENG. J. MED. 1422 (1994); *see also* Don C. Des Jarlais et al., *Sounding Board: Targeting HIV-Prevention Programs*, 331 NEW ENG. J. MED. 1451 (1994).

¹⁵² U.S. CONG. HOUSE OF REPRESENTATIVES, SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL, *INTRAVENOUS DRUG USE AND AIDS: THE IMPACT ON THE BLACK COMMUNITY* I, 129 (1988) (Superintendent of Documents number Y4.N16:100-1-15). The point is that, "Where injection drug use and urban poverty are prevalent, HIV/AIDS has been superimposed on already high mortality rates in young adults." Sten H. Vermund, *Rising HIV-Mortality in Young Americans*, 269 JAMA 3034, 3035 (1993).

¹⁵³ The Article reported a sense of despair at the 1988 international AIDS conference because AIDS consistently was linked to social class and the poor who are more likely to use intravenous drugs. *Poverty Spreads AIDS*, 117 NEW SCIENTIST 26 (1988). Socio-economic conditions have a significant impact on HIV transmission. *See generally* CDC, *AIDS Among Racial/Ethnic Minorities—United States, 1993*, 43 MORBIDITY & MORTALITY WKLY. REP. 644, 654 (1994) ("Socioeconomic status in particular is associated with morbidity and premature mortality Therefore, the social, economic, and cultural context for HIV infection should be considered").

ghettos into what the bath houses were for homosexual men during the 1970s: a facilitator for the virus.¹⁵⁴

This geographical concentration of poverty is demonstrated in the data from the 1970 census showing that in the nation's fifty largest cities, sixteen percent of the nation's poor lived in poverty areas (tracts where at least forty percent of the population was poor). By 1980, twenty-four percent of the poor lived in poverty areas,¹⁵⁵ creating a picture of minority America where the National Urban League in its *State of Black America, 1988*, reports that:

[Twenty-five percent] of all black households are affected by crime. Rates of drug use, crime, and violent death are dramatically higher among blacks and Hispanics than among whites. Forty percent of black children are raised in fatherless homes. Rates of teenage pregnancy, infant mortality, and youth unemployment mark the continued deterioration of the old ghetto—from which much of the minority middle class has already escaped. The status of inner cities as separate and unequal zones in American life has been reinforced beyond the Kerner Report's predictions.¹⁵⁶

These particular ghettos are where the AIDS virus is most concentrated, just as it was in the homosexual ghettos where the virus spread so rapidly in the past. The statistics pinpoint the graphic connection among drugs, geographical ghettos and HIV:

During 1981-86, in New York City, the number and rate of pneumonia deaths among younger persons increased in association with HIV infections in intravenous drug abusers. In addition, data from CDC's 121 Mortality Surveillance System suggest that similar trends may be occurring in other cities.¹⁵⁷

By 1988, studies in New York City indicated that deaths due to infections such as pneumonia, endocarditis, and pulmonary tuberculosis occur

¹⁵⁴ See Raymond C. O'Brien, *AIDS: Perspective on the American Family*, 34 VILL. L. REV. 209, 221 (1989).

¹⁵⁵ Mary Jo Bane & Paul Jargowsky, *Urban Poverty and the Underclass: Basic Questions*, Paper presented at the APPAM Conference, Washington D.C., Oct. 1987, quoted in QUIET RIOTS, *supra* note 78, at 79. See also COMMON DESTINY, *supra* note 127.

¹⁵⁶ QUIET RIOTS, *supra* note 78, at 156.

¹⁵⁷ CDC, *Increase in Pneumonia Mortality Among Young Adults and the HIV Epidemic—New York City*, United States, 37 MORBIDITY & MORTALITY WKLY. REP. 593 (1988). See also Dennis Osmond et al., *Changes in AIDS Survival Time in Two San Francisco Cohorts of Homosexual Men, 1983-1993*, 271 JAMA 1083 (1994); John P. Phair, *Effectiveness of Zidovudine in Treatment of Advanced HIV Infection*, 271 JAMA 1121 (1994); Sten H. Vermund, *Rising HIV-Related Mortality in Young Americans*, 269 JAMA 3034 (1993).

more frequently among IVDUs [Intravenous Drug Users] with HIV infection than among IVDUs without HIV infection.¹⁵⁸

AIDS incidence is highest in the most populous metropolitan areas in the United States Blacks and Hispanics continue to be disproportionately represented among persons with AIDS, particularly among those who were IVDUs or sex partners or children of IVDUs These findings emphasize the need for community-based HIV prevention programs in areas with a high prevalence of drug use, especially among minorities.¹⁵⁹

Among IV drug users (IVDUs), seroprevalence of HIV antibody is highest in New York City and Puerto Rico (45%-60%), high in the Northeast, and low in the Central and Southwestern United States. The high seropositivity levels in the New York City area and Puerto Rico indicate the potential for rapid transmission of HIV to uninfected IVDUs unless effective HIV education and prevention programs are developed for IVDUs in areas of the United States where seroprevalence is presently low.¹⁶⁰

Thus, drug usage and diseases like measles, tuberculosis or syphilis, do not pinpoint prevalence of HIV/AIDS, but they are a prevalent factor. For African-Americans and Hispanics, it has been the most propitious factor and this has the potential to be racist in its application for health care. If the perception is that an infant born into an environment of drugs, tuberculosis, syphilis, measles and now HIV, has no chance of survival, then this is an argument to justify nontreatment.¹⁶¹ The economic reality of no insurance, inadequate Medicaid coverage and a lack of health-care staff bolsters this argument. Finally,

¹⁵⁸ CDC, *Update: Acquired Immunodeficiency Syndrome Associated with Intravenous-Drug Use—United States*, 38 MORBIDITY & MORTALITY WKLY. REP. 165, 169 (1989).

¹⁵⁹ CDC, *Update: Acquired Immunodeficiency Syndrome—United States, 1981-1988*, 38 MORBIDITY & MORTALITY WKLY. REP. 229, 235 (1989). Definite geographical areas, such as Florida, Newark, New Jersey and New York City offer conclusive proof of the link among poverty, ghettos, drug use, HIV and the host of opportunistic infections that plague adults and children alike. See *id.* at 236-50.

¹⁶⁰ CDC, *Coordinated Community Programs for HIV Prevention Among Intravenous-Drug Users—California, Massachusetts*, 38 MORBIDITY & MORTALITY WKLY. REP. 369, 373 (1989) (article describes community programs in Sacramento, California, and Worcester, Massachusetts). For a program in Washington D.C., where the 1988 annual incidence rate was very high, 81.2 cases per 100,000 persons, see Brooke A. Masters, *Network of Churches To Enlist in Drug War*, WASH. POST, Aug. 3, 1989, at C1.

¹⁶¹ See, e.g., Crossley, *supra* note 52, at 1596.

Women who use drugs during pregnancy are more likely to give birth to low birth weight babies and to suffer perinatal complications, either of which may create serious medical problems for the newborn. In addition, the newborn may require intensive medical care for drug withdrawal. Thus, maternal prenatal drug use not infrequently takes a heavy toll on infants infected with HIV and may set the stage for selective nontreatment by giving rise to a condition requiring life-saving treatment for the infant.

Id.

the fact that almost all of these infants are of color creates an argument of racial discrimination. Medicare would provide automatic health care with possible concomitant increases of medical staff and services. This is why children should be included within Medicare.

IV. POVERTY

Drugs and geography go together, as do socioeconomic status and geography. This is true for the United States and for the rest of the world.¹⁶² Today, poverty is where you find AIDS, and in that poverty, like the discrimination associated with HIV, confusion and racism contributes to the selective nontreatment of women and children with AIDS. This is a reason for including children within Medicare. Protection under the ADA, applicable state statutes on child abuse and arguments based on morality or ethics cannot meet the daily need for health care within poor areas of America.

The connection between HIV and poverty is illustrative. The connection begins with intravenous drug use. The HIV infection has expanded to urban inner-city ghettos from the predominantly homosexual ghettos of the city, and the socioeconomic status can be defined as welfare-poverty. Nevertheless, to use the phrase welfare-poverty does not seem to grasp the picture of homelessness and the "cycle of poverty" that grips many of these inner-cities.¹⁶³ A description from Lisbeth Schorr's book, *Within Our Reach: Breaking the Cycle of Disadvantage* may be of assistance:

¹⁶² The spread of HIV in the United States mirrors that of the international community. Most of the cases reported concerned homosexual men in affluent Western nations, but as the years have passed, the disease has become most voracious in poor third-world nations. Marsha F. Goldsmith, *AIDS Around the World: Analyzing Complex Patterns*, 259 JAMA 1917, 1719 (1988) (133 nations have reported cases. By 1990, almost one million cases are expected to be reported, and ten million people will be infected.); Peter Piot et al., *AIDS: An International Perspective*, 239 SCIENCE 573 (1988) (A global education and information campaign is needed to stop the spread of the disease.); see generally Kevin DeCock et al., *The Public Health Implications of AIDS Research in Africa*, 272 JAMA 481-86 (1994); Michael E. Samuels et al., *Containing the Spread of HIV Infection: A World Health Priority*, 103 PUB. HEALTH REP. 221-23 (1988).

¹⁶³ Professor Crossley identifies the connection between poverty and the infant born with AIDS. She writes:

For most people who ever have the occasion to read a law review article, imagining with any accuracy the world into which most perinatally infected infants are born is probably difficult. The setting is urban and poor. The family is ravaged by intravenous drug use, AIDS, or both, and may not have the financial, social, or emotional wherewithal to care for the baby.

Crossley, *supra* note 52, at 1598-99.

In [welfare-poverty] areas, more than half of the men worked less than twenty-six weeks the previous year, more than a third of the men and women between the ages of sixteen and nineteen had dropped out of school, more than a third of the households received welfare assistance, and well over half (57%) of the families were headed by women.¹⁶⁴

Of course, this is where being African-American and Hispanic takes on added dimension, for most of the persons living in these urban ghettos are minorities. In the 880 census tracts used in 1980, fifty-eight percent of the population was black, eleven percent was Hispanic and twenty-eight percent was white. Thirty-six percent of the population was children.¹⁶⁵ Just as the earliest cases of AIDS started in homosexual-minority ghettos, so do present cases of HIV occur in African-American and Hispanic-minority ghettos.

"The geographic distribution of black and white poor populations is not alike."¹⁶⁶

Poor blacks, to a much greater degree than poor whites, interact mainly with other disadvantaged people. Black poor children attend schools with other poor children, go to churches with impoverished congregations, and deal with merchants geared to do business with poor clientele. Racial segregation in residence reinforces the effects of economic separation.¹⁶⁷

It is difficult to make general statements, but the statistics do show that 31.1 percent of the black poor and 12.0 percent of the white poor live in central cities.¹⁶⁸ In cities with the highest concentration of HIV persons, the incidence of black poor is the highest:

¹⁶⁴ LISBETH SCHOOR, *WITHIN OUR REACH: BREAKING THE CYCLE OF THE DISADVANTAGED* 17 (1988).

¹⁶⁵ *Id.*

¹⁶⁶ Crossley, *supra* note 52, at 1591.

¹⁶⁷ *Id.* at 1598.

¹⁶⁸ U.S. DEPT. OF COMMERCE, ECON. & STAT. ADMIN., BUREAU OF THE CENSUS, 1990 UNITED STATES CENSUS OF POPULATION, SOCIAL AND ECONOMIC CHARACTERISTICS, METROPOLITAN AREAS 352, 406 (1990).

TABLE 3
CONCENTRATION OF POVERTY BY RACE IN 1990:¹⁶⁹
AVERAGE PERCENTAGE OF POPULATION POOR
IN CENSUS TRACT OF TYPICAL POOR PERSON

	BLACK	WHITE
NEW YORK CITY	25.3	12.0
PHILADELPHIA	28.8	11.2
LOS ANGELES	24.5	12.3
WASHINGTON D.C.	19.9	08.2
HOUSTON	31.2	12.4
DALLAS	28.8	09.3
NEWARK	29.2	14.9
SAN FRANCISCO	22.1	09.3
NEW ORLEANS	42.2	11.2

Poor geographical neighborhoods—ghettos—are certainly likely to be significant harbors of HIV, and to the extent that blacks and Hispanics can escape their borders, this will result in one less opportunity for infection. Few escape. It is part of the scandal that, “to the extent that escaping from poverty may be facilitated by living in more prosperous neighborhoods, poor whites have a great advantage over poor blacks.”¹⁷⁰ Living far from poverty may have the same beneficial consequences for minorities as living far from the bath houses had for many homosexual men: opportunities of infection with HIV are fewer.

Of course, there is an added element in the connection affecting poor inner-city minorities that was not significantly present when the disease began in the homosexual ghettos. That is the element of children. Since 1986, “the largest increases in new cases [of HIV] have been observed in two groups: Heterosexual partners of HIV-infected individuals and children whose mothers abuse drugs or are sexual part-

¹⁶⁹ *Id.* Poverty statistics census publications presented were based on a definition the Social Security Administration originated in 1964. The definition was modified later by Federal inter-agency committees in 1969 and 1980 and prescribed by the Office of Management and Budget's Directive 14 as the standard to be used by federal agencies for statistical purposes. *Id.* at B-27. For additional consequences of socioeconomic status, see Robert S. Hogg et al., *Lower Socioeconomic Status and Shorter Survival Following HIV Infection*, 344 LANCET 1120 (1994).

¹⁷⁰ Crossley, *supra* note 52, at 1596.

ners of men at high risk. There is an over-representation of African-Americans and Hispanics in both of these groups."¹⁷¹ This trend certainly shall continue, but the element of children suffering should not be the main reason for taking charge of the emergency situation at hand.

When confronted with the horror of disease, concern over the fault of an adult and the innocence of a child is totally unethical. Instead, the numbers, the inescapable discrimination, racism, poverty and the inescapable conclusion that we know exactly where the disease is geographically concentrated make anything less than total response a scandal. There must be a better community response than nontreatment of persons victimized by nontreatment for most if not all of their lives. But what should be the community response when it faces catastrophic costs and even an attack upon the entire community's health care fabric?

V. SPECIFIC ARGUMENTS

A. Financial Responsibility

Any discussion of why inclusion of children within Medicare is justified must begin with the acknowledgement that vast amounts of resources presently go to the care and welfare of adults. This may be justified upon the theory that adults have contributed more, that they are older and thus more prone to illness and assistance, or perhaps that they can vote and thus direct more public dollars in their direction. Thus, the essential question should be whether children are treated fairly in the allocation of health care resources. To answer, it is useful to again return to the AIDS pandemic and examine the allocation of resources.

An example of the human and financial costs associated with HIV occurred in the early fall of 1989. It was described in *The Washington Post*. It is the story of Juella, thirty-five years-of-age, a life-long resi-

¹⁷¹ CONFRONTING AIDS, *supra* note 86, at 51. See generally, Pamela Boyer et al., *Factors Predictive of Maternal-Fetal Transmission of HIV-1*, 271 JAMA 1925 (1994); CDC, *Human Immunodeficiency Virus Transmission in Household Settings—United States*, 43 MORBIDITY & MORTALITY WKLY. REP. 347 (1994); Steven Douglas, *Immunological and Virological Clues for Mother-to-Child Transmission of HIV-1 and HIV-2*, 272 JAMA 487 (1994); European Collaborative Study, *Caesarean Section and Risk of Vertical Transmission of HIV-1 Infection*, 343 LANCET 1464 (1994); Srisakul Kliks et al., *Features of HIV-1 That Could Influence Maternal-Child Transmission*, 272 JAMA 467-74 (1994); Richard D. Semba et al., *Maternal Vitamin A Deficiency and Mother-to-Child Transmission of HIV-1*, 343 LANCET 1593 (1994).

dent of Newark, New Jersey, and someone who thinks that AIDS runs in her family.

Her 42 year-old husband died of the disease. So did her 27-year-old brother and her aunt. Several weeks ago, her terminally ill younger sister was released from New York's Bellevue Hospital after months of treatment for AIDS [Juella] apparently contracted the AIDS virus through sex with her husband. Several weeks ago, she developed a throat infection and now she is a patient on the same floor of the same hospital where her husband died on July 6. She spends most of her time thinking about how her death will affect their three healthy children, who range in age from 10 to 19.¹⁷²

Juella is an Hispanic woman in a vector of the inner-city cordoned by syphilis, tuberculosis, measles, poverty and drugs. Because of these factors, she has experienced discrimination and racism. Look at the statistics, and it is readily apparent that she is among those in clear and present danger of HIV. The statistics when Juella was diagnosed are familiar: More than seventy-five percent of Newark's 1409 HIV cases are drug-related, and ninety percent are black or Hispanic.¹⁷³ New Jersey has the largest number of AIDS cases among women and ranks second in the number of pediatric cases.¹⁷⁴ One-third of the population in Newark lives below the poverty line, the infant mortality rate is double the national average, the wait for drug treatment ranges from three to nine months and the percentage of homeless people is three times that of New York City.¹⁷⁵ More importantly the average cost of caring for an AIDS patient is about \$200,000, much of which public hospitals bear with very few alternatives available to lessen the expense of hospital care.¹⁷⁶ Nearly half the patients are uninsured, and even

¹⁷² Sandra G. Boodman, *Up Against It*, WASH. POST HEALTH, Sept. 5, 1989, at 12.

¹⁷³ *Id.* at 13-14.

¹⁷⁴ *Id.* at 14.

¹⁷⁵ *Id.*

¹⁷⁶ Note that for many black and Hispanic persons, most of whom are HIV-infected as a result of drug use, the health care and services used by many homosexual persons with AIDS are not available—not because of discrimination, rather, because homosexuals tend to belong to a different socio-economic group, located far from the particularized ghettos. *Id.* at 14. With many of the black and Hispanic infected with HIV,

[t]here is no housing for AIDS patients, no hospice care and no place other than a nursing home 30 miles away that will accept patients who don't need the expensive technology of a teaching hospital and trauma center. The city's fledgling AIDS organization, the Newark Community Project for People With AIDS, was founded only last year (1988). By contrast, its counterparts in New York and San Francisco began operating in 1981, before AIDS had been named.

Id. at 14.

though New Jersey has a progressive Medicaid program, it does not cover all of the costs.

Current estimates are that the cost for treating a person with AIDS actually has fallen as a result of reduction in the use of hospital inpatient services and the rise in hospital outpatient services.¹⁷⁷

It is estimated that the lifetime cost of treating a person with HIV from the time of infection until death is approximately \$119,000. The estimated cost of care from HIV infection until the development of AIDS is \$50,000, while the estimated cost from AIDS development until death is approximately \$69,000.¹⁷⁸

There are a number of essential points to be made in acknowledging the reduction in costs associated with AIDS treatment. First, costs have fallen even though treatment occurs from the first knowledge of infection through the actual development and death from opportunistic infections. This later stage is identified as actual AIDS. Second, people with AIDS actually are living longer: "Although it is difficult to prove, treatment of HIV has likely resulted in prolonging the life of HIV-infected individuals and improving their quality of life."¹⁷⁹ Third, partly because of advances in drug therapy, outpatient treatment has resulted in reduced costs.¹⁸⁰

Fourth, "[a] number of preventive health measures can improve the health and quality of life of persons infected,"¹⁸¹ and these measures can be provided at less cost than in the past. Fifth, outpatient services—services that do not require a hospital stay—have caused the reduction in costs. And sixth, infants with AIDS are not likely to be the beneficiaries of reduced costs, because there will be fewer outpa-

¹⁷⁷ Fred J. Hellinger, *The Lifetime Cost of Treating a Person With HIV*, 270 JAMA 474 (1993). "In the past, the proportion of costs attributable to outpatient services has risen concomitantly with the total cost of treating PWAs." *Id.* at 478. The point is that, as hospitals treat more people with AIDS, the costs associated with the disease fall while hospitals develop less costly treatment methods to include greater reliance upon out patient services.

¹⁷⁸ *Id.* at 474.

¹⁷⁹ Margaret Johnston & Daniel Hoth, *Present Status and Future Prospects for HIV Therapies*, 260 SCIENCE 1286 (1993).

¹⁸⁰ Criticism continues over government funding of research. See, e.g., *id.* at 1291. "Overall, substantial resources have not been devoted to the pursuit of potential drug targets . . . and even fewer resources have been devoted to more innovative and risky approaches to restore immune function." *Id.*

¹⁸¹ John F. Jewett & Frederick M. Hecht, *Preventive Health Care for Adults With HIV Infection*, 269 JAMA 1144, 1149 (1993). See also Michael H. Merson, *Slowing the Spread of HIV: Agenda for the 1990s*, 260 SCIENCE 1266 (1993).

tient services available to them.¹⁸² Targeting more community-sponsored outpatient programs would result in certain cost savings.¹⁸³

What are some of the costs involved? Drug therapy is always expensive and variable in cost. AZT can have an annual per patient cost of \$8000 to \$10,000—at the time Burroughs Wellcome was given a seventeen-year patent and exclusive right to sell the drug, it was the most expensive drug ever marketed.¹⁸⁴ Pentamidine, a drug for the treatment of *Pneumocystis carinii* pneumonia, retailed at \$24.95 per vial in 1984, but by 1987, the cost had risen to \$95.49 per vial.¹⁸⁵ By February 1989, the price had been set at \$99.45, with a one-year supply costing about \$1200. “When costs of inhaler machines and labor are taken into account, the annual cost could run to \$2,100 for outpatient therapy.”¹⁸⁶ Part of this increase in cost is due to the change in form of the drug, a change to aerosol that has proven to be very beneficial. But part of the increase is due to the lack of alternative drugs. There is an absence of competition, and this relates to the method by which the Orphan Drug Act sponsors new drugs.

Data indicate that for HIV-infected persons without the opportunistic infections associated with AIDS, the “average monthly cost for

¹⁸² Most infants with AIDS remain in hospitals. “Finding foster families willing to care for an HIV-infected infant can be difficult, and as a result, infants left in a hospital nursery by their mothers may stay in the hospital longer than medically necessary.” Crossley, *supra* note 52, at 1599-1600.

¹⁸³ This is in fact what is meant by persons such as David E. Rogers when he writes in an editorial, “We should provide adequate funding for intense, targeted education that is imaginatively directed at high-risk groups, particularly teenagers.” David E. Rogers, *Federal Spending on AIDS—How Much Is Enough?* 320 NEW ENG. J. MED. 1623, 1624 (1989). In a related fashion, he writes, “We should provide federal funds for disaster relief to help the cities most seriously affected by AIDS.” *Id.* See also CONFRONTING AIDS, *supra* note 86, at 17 (recommending federal grant programs for hard-hit communities). For one reason why this is not done, see generally JONATHAN KOZEL, RACHEL AND HER CHILDREN: HOMELESS FAMILIES IN AMERICA (1988).

¹⁸⁴ COMMITTEE ON GOV'T OPERATIONS, AIDS DRUGS: WHERE ARE THEY?, H.R. REP. NO. 100-2092, 100TH CONG., 2d Sess. 31 (1988).

Burroughs Wellcome has never agreed to make public its portion of the cost of developing and producing AZT, nor adequately justified the extremely high price of the drug. Company representatives testified at a Congressional hearing in March 1987 that research and development costs had been \$80 million. The cost of AZT to Federal and State governments under the Medicaid Program was \$20 million in FY 1987.

Id. at 32.

¹⁸⁵ *Id.*

¹⁸⁶ Warren E. Leary, *F.D.A. Allows Wider Use of Drug to Prevent Pneumonia in AIDS Patients*, N.Y. TIMES, Feb. 7, 1989, at B6. Aerosol pentamidine's cost is much less than hospitalization and treatment for a single episode of pneumonia. That cost would be more than \$12,000. *Id.*

prescription drugs . . . is \$99.”¹⁸⁷ For a person who has opportunistic infections, “the monthly cost of prescription drugs was \$265”¹⁸⁸ These costs assume the patient has access to programs that may reduce costs,¹⁸⁹ and often that the patient is not among the many who shall continue injurious behaviors, such as drug use, random sexual encounters and poor living conditions.

Now look to children. The National Institute of Allergy and Infectious Diseases’ (NIAID) announcement that AZT should be given to all pregnant women because there was significant evidence that the drug reduced transmission of HIV from infected mothers to infants caused great excitement. But it causes concern similar to that which the announcement made in 1989 caused:

AZT, the only licensed drug [at that time] to treat AIDS, should be given to people who show the earliest signs of the disease, raises one of the most difficult questions of the epidemic: How will those who need AZT, increasing numbers of whom are poor intravenous drug users, pay for a drug that costs an average of \$8,000 per year?¹⁹⁰

Will health insurance, Medicaid or outright tax dollars pay to keep the poor, the homeless, the prostitutes and the other people who hang out in “shooting galleries” alive? Why should the government spend money on AZT to keep infants alive when there are proposals to reduce welfare for women who have additional babies, and there are additional proposals to insert Norplant, a birth control device, into the arms of pregnancy-prone women?¹⁹¹

¹⁸⁷ Fred J. Hellinger, *The Lifetime Cost of Treating a Person With HIV*, 270 JAMA 474, 476 (1993).

¹⁸⁸ *Id.* The cost is less in states, such as New York, which has an AIDS Drug Assistance Project (ADAP). Rates reimbursed by ADAP generally are lower than those paid by individual purchasers.

¹⁸⁹ It is logical to assume that availability of such programs may be limited severely in certain geographical areas most inhabited by women and children with AIDS. Thus, crowding, severe shortfalls in public revenues and inadequate staffing may make drugs more expensive or, more likely, beyond reach for the persons most likely to be victimized by selective nontreatment. See, e.g., Dennis Andrus et al., *Comparison of Hospital Care For Patients With AIDS and Other HIV-Related Conditions*, 267 JAMA 2482 (1992).

¹⁹⁰ Sandra G. Boodman, *The Dilemma of AZT: Who Can Afford It?* WASH. POST HEALTH, Aug. 8, 1989, at 6. See also Dant Bolognesi, *Prospects for Prevention of and Early Intervention Against HIV*, 261 JAMA 3007, 3012 (1989) (“as in most other biomedical problems, the earlier the intervention, the more favorable the outcome”); Brooke Masters, *AZT Found to Delay Onset of AIDS; Treatment Urged for Up to 650,000*, WASH. POST, Aug. 18, 1989, A1; Michael Specter, *Early AIDS Treatment Urged*, WASH. POST, Aug. 4, 1989, at A1.

¹⁹¹ See, e.g., Michael T. Flannery, *Norplant: The New Scarlet Letter?* 8 J. CONTEMP. HEALTH L. & POL’Y 201 (1992).

Whenever the question of cost arises, it must be seen within the context of people of color, living alternative lifestyles. Will society be willing to pay the cost—no matter what that cost is—for such a person? Cost is associated with discrimination, racism and poverty. Further, because HIV will continue to be involved predominantly with persons in certain states such as New York, New Jersey, California, Florida and Texas, where more than two-thirds of the cases are present, how will those localities pay the cost?¹⁹² How will the federal government respond?

Insurance companies affect the costs. For instance, as the FDA and NIAID were announcing “parallel tracks” and accelerated clinical trials on new AIDS drugs, some insurance companies refused to pay for AZT and drugs other than those listed by the Food and Drug Administration. In short, the insurance companies, in an effort to reduce health costs,¹⁹³ denied payment for promising drugs because the medication was experimental. “Until recently, once a drug was approved, physicians could prescribe it as they saw fit. That widespread and long-standing medical practice, known as ‘off label’ use, is believed to account for more than half of all prescriptions written annually.”¹⁹⁴ Thus, the insurance companies serve as another reviewing agency, only paying for those medical treatments that have been proving themselves and

¹⁹² Dr. David Axelrod, Health Commissioner for the State of New York, has proposed a plan to provide health insurance to the 2.5 million New Yorkers who have none by requiring all businesses to provide coverage to their employees and by using up to one billion dollars from a “bad debt and charity pool” for uninsured people. See Sam Howe Verhovek, *New York Health Chief Proposes Medical Insurance for All in State*, N.Y. TIMES, Sept. 7, 1989, at A1.

¹⁹³ Already, almost all insurance companies now refuse to insure individual health insurance applicants with AIDS, and 91% refuse to insure those with antibodies to HIV. Health insurance companies “screen” applicants for individual and small group health insurance policies by including AIDS-related questions on the health history portion of their applications, but to date, companies do not question individuals covered under employment-related group policies. CONFRONTING AIDS, *supra* note 86, at 112-13; Bloom & Carliner, *The Economic Impact of AIDS in the United States*, 239 SCIENCE 604-10 (1988) (some states have enacted legislation to prohibit HIV testing by insurance companies, but the companies can then refuse to write policies there or include clauses limiting coverage for AIDS).

¹⁹⁴ Sandra G. Boodman, *The Dilemma of AZT: Who Can Afford It?* WASH. POST HEALTH, Aug. 8, 1989, at 6. See, e.g., CDC, *Fansidar-Associated Fatal Reaction in an HIV-Infected Man*, 37 MORBIDITY & MORTALITY WKLY. REP. 571 (1988). The National Task Force on AIDS Drug Development continues to recommend inclusion of women and children in all clinical trials, sanctions against companies whose trials exclude women unnecessarily and elimination of the requirement of consent from the father of a child for inclusion when the woman is pregnant. See Paul M. Rowe, *Lowering the U.S. Hurdles for Aids Drugs*, 345 LANCET 247, 248 (1995). The inclusion of women has resulted in insights into prevention and treatment. See, e.g., William E. Paul, *Reexamining AIDS Research Priorities*, 267 SCIENCE 633 (1995).

demanding a lengthy payment time. Thus, those who cannot pay for the medication themselves are denied the benefit of the Congressional Report "that experimental drugs should be as widely available as possible to persons with life-threatening illnesses if they are safe and have demonstrated efficacy."¹⁹⁵

Clinical trials affect treatment costs. For instance, often, HIV-infected persons have access to experimental drugs because of clinical trials.¹⁹⁶ But we have seen these trials traditionally have excluded women, children and drug users, and most of these persons are also black or Hispanic.¹⁹⁷ The trials also are centered in specific geographic locations, meaning participants may have to travel long distances, often at the expense of employment. If they lose their jobs, they also lose their health insurance. The trials can be very impersonal, and there can be language barriers. Most importantly, the trials often are controlled, using placebos, placing a participant in the position of possibly receiving a sugar pill, rather than the experimental medication. If a person can afford to pay for what he or she knows is in fact the drug about which some good has been written or said, a clinical trial offers no allure.

If no trial is available, and the insurance company will not pay for the medication—or the patient has no insurance—Medicaid is an alternative. But how much longer can Medicaid provide benefits? Expenditures for Medicaid were \$49 billion in 1987, and the projection is that the program will cost \$260 billion in 1997.¹⁹⁸ One-hundred twenty-seven billion dollars was spent in 1992.¹⁹⁹ States such as Oregon exclude payment for any service that the state deems to have low priority, regardless of whether the treatment is medically necessary under prevailing legal standards. An increasingly attractive alternative is the Medi-Cal (California Medicaid), in which the proportion of persons with AIDS who Medicaid assisted rose from twelve percent to twenty

¹⁹⁵ COMMITTEE ON GOVERNMENT OPERATIONS, *supra* note 184, at 31.

¹⁹⁶ Approximately 6200 of the persons with AIDS are enrolled in federally funded therapeutic trials. David Rogers, *Federal Spending On AIDS—How Much is Enough?* 320 NEW ENG. J. MED. 1623, 1623 (1990) (editorial supports the position that the federal government is spending too little on AIDS). See also THOMAS PHILIPSON & RICHARD POSNER, PRIVATE CHOICES AND PUBLIC HEALTH: THE AIDS EPIDEMIC IN AN ECONOMIC PERSPECTIVE (1993); Fred Hellinger, *The Lifetime Cost of Treating a Person With HIV*, 270 JAMA 474, 478 (1993).

¹⁹⁷ Rogers, *supra* note 196, at 1624-25.

¹⁹⁸ Janet Novack, *Hemorrhage*, FORBES, Sept. 28, 1992, at 77.

¹⁹⁹ *Id.*

percent between 1985 and 1986 alone.²⁰⁰ For hospitals providing care to persons with AIDS, Medicaid is the preponderant source of payment, and in locations such as New York and New Jersey, between sixty-five and seventy percent of all persons with AIDS are covered by Medicaid. As the demographics of the epidemic spread even further into the lower socioeconomic populations, these numbers will increase.²⁰¹

The amount and scope of Medicaid coverage affects the costs associated with AIDS, and this coverage varies significantly among the states. There is an argument that the changes in drug testing at the FDA will only augment the disparity between a Medicaid patient's coverage in comparison with that of a wealthier patient. For instance, "Medicaid programs in every state cover AZT, but many will pay for the drug only after people have gotten sick, and not as a preventive measure for those who are infected with the virus and show no signs of disease."²⁰² Of course these asymptomatic persons are just the ones proven to benefit from early introduction to AZT. Documentation shows this to be true for pregnant women and the unborn fetus as well.²⁰³

Yet, where do we draw the line on costs when it is estimated that between one and 1.5 million persons are HIV-infected? "Medicaid is estimated to cover about 40 percent of all patients with AIDS and about 25 percent of the total U.S. cost for AIDS-related personal health care. Again, the cumulative federally financed Medicaid costs

²⁰⁰ CONFRONTING AIDS, *supra* note 86, at 112.

²⁰¹ A survey by the National Public Health and Hospital Institute examined 623 acute-care hospitals, and 322 responded. In this most recent study, 276 hospitals reported treating persons with AIDS for an average stay of 16.8 days. Cost per patient per day was \$681, and revenues per patient per day were \$545. Cost for each patient for one year was \$17,910. Estimated total cost for AIDS inpatient care during 1987 was \$486 million, with Medicaid as the primary payer. Dennis P. Andrulis et al., *The U.S. Hospital AIDS Survey*, 262 JAMA 784 (1989).

²⁰² Boodman, *supra* note 190, at 6. As of 1988, 44 states covered AZT through the Medicaid programs, and two other states paid for it only during hospital care. This variation in coverage is indicative of unfairness. "Poor states are unlikely to offer the range of services and coverage that wealthier states can provide." CONFRONTING AIDS, *supra* note 86, at 114-15.

²⁰³ CDC, *Zidovudine for the Prevention of HIV Transmission from Mother to Infant*, 43 MORBIDITY & MORTALITY WKLY. REP. 285 (1994); CDC, *Recommendations of the U.S. Public Health Service Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of Human Immunodeficiency Virus*, 43 MORBIDITY & MORTALITY WKLY. REP. RR-11 (1994). See also Stephanie Blanche et al., *Relation of the Course of HIV Infection in Children to the Severity of the Disease in their Mothers at Delivery*, 330 NEW ENG. J. MED. 308 (1994); Richard D. Semba et al., *Maternal Vitamin A Deficiency and Mother-to-Child Transmission of HIV-1*, 343 LANCET 1593 (1994).

for AIDS to date are estimated at \$1260 million."²⁰⁴ It was thought that "an effective treatment [including early use of AZT] for HIV infection to prevent the onset of AIDS could result in large increases in medical costs, because thousands would enter treatment."²⁰⁵ However, because of outpatient care, this increase has not resulted. But what of the future, and particularly those persons within the context of drugs, STDs, tuberculosis and measles? Eventually, should HIV persons continue to live longer, Medicare will be required to assist more than the one percent of all persons with AIDS as it does now. This will result from the fact that more persons will survive the twenty-four-month waiting period needed to qualify for benefits.²⁰⁶

The federal and state governments must work together to address the local need generated by differing patterns of HIV-infection and the disparity among various Medicaid state programs.

The law requires coverage of certain mandatory services—for example, inpatient and ambulatory hospital care (although the state may limit the number of hospital days covered or the level of services reimbursed), physician services, and skilled nursing facility and home health care for individuals aged 21 and older. Additional services may be offered at the state's discretion, including prescription drugs, intermediate care, hospice care, case management, and personal care services.²⁰⁷

Many states, particularly in the poorer South, have eligibility criteria that deny coverage to persons who might be eligible for coverage in other states. Further, public hospitals in these states often are left without reimbursement because neither Medicaid nor health insurance

²⁰⁴ William Winkenwerder et al., *Federal Spending for Illness Caused by the Human Immunodeficiency Virus*, 320 NEW ENG. J. MED. 1600 (1989). Two additional programs provide cash assistance to persons with AIDS or HIV-related illnesses: Disability Insurance and Supplemental Security Income, with \$260 million and \$69 million respectively in cumulative expenditures to date. *Id.*

²⁰⁵ *Id.* at 1601. Even when compared to other drugs such as ddC, AZT has substantial advantages "in terms of functional outcomes such as symptom impact, disability, work, utilization, and health status." Samuel A. Bozzette et al., *Health Status and Function With Zidovudine or Zalcitabine as Initial Therapy for AIDS*, 273 JAMA 295 (1995). There is considerable debate as to the efficacy of early treatment with AZT. See, e.g., John G. Bartlett, *Zidovudine Now or Later?*, 329 NEW ENG. J. MED. 351, 352 (1993) (a pessimistic appraisal of early treatment with AZT).

²⁰⁶ Medicare covers AIDS patients through its disability program, which is tied to the Social Security Disability program. To be eligible, disabled workers must first meet the Social Security requirements for "insured status" and must be considered disabled according to the program's definition. They can then receive Social Security disability benefits for 24 months, after which they may begin to receive benefits under Medicare. CONFRONTING AIDS, *supra* note 86, at 112.

²⁰⁷ *Id.* at 114.

is able to pay for treatment. This affects that quality of care for all persons and challenges the ability of public hospitals to survive.²⁰⁸

Health care reform could have an impact on costs, but in what form? If government is to meet the financial and human cost of the HIV epidemic, it must address the United States health care system. This is a massive task and not achievable within the short time in which millions of persons—many of them African-American and Hispanic—will require assistance to live. Nonetheless, even the smallest contribution to health care assistance should have the ancillary goal of contributing to a better health care system.²⁰⁹ When cities, then states, then the federal government realize in the few years that it shall take that private insurance, private wealth or government protocols are keeping the privileged few alive, and that Medicaid and Medicare is costing billions of dollars but still excluding some such as children, it will be too late.

Finally, private groups are seeking to have an impact on costs and a fairer system of health care. The American College of Physicians made the following recommendations in 1988:²¹⁰

- (1) Providing incentives through the tax system or through other favorable treatment of insurers to increase the availability of open enrollment policies.
- (2) Subsidize private insurance premiums for lower income persons.
- (3) Protect the financial integrity of insurers from adverse selection in which some of the insurance companies, because of their more favorable policies, assume a disproportionate share of AIDS related health insurance costs. Protection could be offered either through direct government assistance or through a system of spreading the costs of insuring HIV-infected persons among insurers.
- (4) Increase the extension-of-coverage period mandated by the 1985 Consolidated Omnibus Budget Reconciliation Act (COBRA), in which an employee leaving work can continue to pay the group rate premium for up to 18 months of additional coverage. If the 24-month waiting period for Medicare eligibility is not reduced, the COBRA extension should be increased to at least 24 months to prevent a gap in coverage.

²⁰⁸ See PRESIDENTIAL COMMISSION, *supra* note 75, at 141-56. See also 1987 U.S. Hospital AIDS Survey, 262 JAMA 784 (1989) (survey concludes that many hospitals that serve large numbers of low-income persons with AIDS have encountered moderate to severe financial shortfalls).

²⁰⁹ See generally, PRESIDENTIAL COMMISSION, *supra* note 75, at 7-72, 141-48; CONFRONTING AIDS, *supra* note 86, at 93-122, 171-201.

²¹⁰ American College of Physicians, *Financing the Care of Patients with Acquired Immune-deficiency Syndrome (AIDS)*, 108 ANN. INTERN. MED. 460, 462-65 (1988), (quoted in CONFRONTING AIDS, *supra* note 86, at 114).

- (5) Provide government subsidies, based on income and resources, for any person exercising the COBRA extension option who cannot afford the premium.

As the government debates these and other recommendations, some states continue to make medical, mental health, social, housing, testing or financial services available to patients with HIV and their families. These local initiatives are funded in part by federal initiatives such as the Ryan White Comprehensive AIDS Resources Emergency Act of 1990.²¹¹ Other states concerned with the financial burden of the epidemic have provided housing for homeless persons with AIDS, created task forces to develop catastrophic health insurance coverage, expanded Medicaid or established a sliding fee for services.²¹² These community responses are needed desperately to augment efforts already made.

This must lead to the conclusion that children are not receiving an equitable share of the health care system in the United States. Perhaps it is because they live with parents who are too poor to afford doctors or medication but are still too wealthy to qualify for Medicaid. While the parent may be employed, perhaps the employer does not provide family coverage that includes the children. And while community-based health care programs are available, often they are for adults, providing adult protocols or adult qualifications. The result is that a child cannot afford to live. Medicare would make living affordable.

B. Legal Responsibility

According to current medical prognosis for an infant with AIDS, at least some infants infected with HIV live longer than five years.²¹³ Debate continues as to how or when HIV is transmitted to the infant

²¹¹ See generally Raymond C. O'Brien, *A Legislative Initiative: The Ryan White Comprehensive Emergency Act of 1990*, 7 J. CONTEMP. HEALTH L. & POL'Y 183-205 (1991).

²¹² Lawrence O. Gosten, *Public Health Strategies for Confronting AIDS*, 261 JAMA 1621 (1989).

²¹³ See Italian Register for HIV Infection in Children, *Features of Children Perinatally Infected with HIV-1 Surviving Longer Than 5 Years*, 343 LANCET 191, 203 (1994). "A new outlook emerges. A substantial number of children do survive after early childhood . . . [and] a CD4 cell decrease early in life can be predictive of outcome." *Id.* See also Micheline Fauvel et al., *Early Detection of HIV in Neonates*, 329 NEW ENG. J. MED. 60 (1993); Sheldon Landesman et al., *Clinical Utility of HIV-IgA Immunoblot Assay in the Early Diagnosis of Perinatal HIV Infection*, 266 JAMA 3446 (1991); Thomas C. Quinn et al., *Early Diagnosis of Perinatal HIV Infection by Detection of Viral-Specific IgA Antibodies*, 266 JAMA 3439 (1991).

by the mother.²¹⁴ This has not stopped litigation regarding liability for transmitting HIV to the infant.²¹⁵ But incontrovertible evidence suggests that an infant could survive longer with advanced medical treatment.²¹⁶ Thus, the important legal issue is: "Can we speak meaningfully of discrimination based on disability in the context of medical treatment decision-making, and, if so, how can we distinguish illegitimate discrimination from the ethical exercise of sound medical judgment?"²¹⁷ In essence, when can a hospital selectively non-treat an infant with AIDS?

The Americans with Disabilities Act (ADA)²¹⁸ prohibits discrimination based on disability in hospitals and other public settings.²¹⁹ It certainly would appear from existing cases and current medical treatment options for infants with AIDS that the ADA should apply protection to these infants for medical decision-making.²²⁰ This would apply

²¹⁴ Pier-Angelo Tovo, *Caesarean Section and Perinatal HIV Transmission: What Next?*, 342 LANCET 630 (1993); Philippe Van de Perre et al., *Infective and Anti-infective Properties of Breast Milk from HIV-1 Infected Women*, 341 LANCET 914 (1993); John B. Ziegler, *Breast Feeding and HIV*, 342 LANCET 1437 (1993).

²¹⁵ See, e.g., *In re Valerie D.*, 613 A.2d 748 (Conn. 1992) (court held that mother's prenatal ingestion of excessive amounts of alcohol during pregnancy resulting in child's fetal alcohol syndrome was not sufficient to terminate her rights in the child); *Johnson v. Florida*, 615 So. 2d 1288 (Fla. 1992) (rejecting state prosecution of mother for "delivering" drugs to fetus prior to her child's birth); *State v. Luster*, 419 S.E.2d 32 (Ga. Ct. App.), cert. denied, (Ga. 1992) (holding that the Georgia state statute did not apply to the transmission of cocaine metabolites to a fetus); *Ohio v. Gray*, 584 N.E.2d 710 (Ohio 1992) (holding that a parent may not be prosecuted for child endangerment for substance abuse occurring before the birth of a child); Martha Marie Curley, Note, *Establishing Relief for the Most Innocent of All AIDS Victims: Liability for Perinatal Transmission of AIDS*, 28 J. FAM. L. 271 (1990).

²¹⁶ Only recently have drug trials included infants. See e.g. Ross E. McKinney et al., *A Multicenter Trial of Oral Zidovudine in Children With Advanced Immunodeficiency Virus Disease*, 324 NEW ENG. J. MED. 1018 (1991); The National Institute of Child Health and Human Development Intravenous Immunoglobulin Study Group, *Intravenous Immune Globulin for the Prevention of Bacterial Infections in Children With Symptomatic Human Immunodeficiency Virus Infection*, 325 NEW ENG. J. MED. 74 (1991); Gareth Tudor-Williams, *HIV-1 Sensitivity to Zidovudine and Clinical Outcome in Children*, 339 LANCET 15 (1992).

²¹⁷ Crossley, *supra* note 52, at 1588.

²¹⁸ 42 U.S.C. §§ 12101-12213 (1994); 47 U.S.C. §§ 225.661 (1991).

²¹⁹ For discussion, see, e.g., Robert L. Burgdorf, Jr., *The Americans With Disability Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413 (1991); Robert L. Burgdorf Jr., Comment, *Insuring Americans With Disabilities: How Far Can Congress Go To Protect Traditional Practices?*, 40 EMORY L.J. 1183 (1991); Stewart R. Hakola & Joseph F. Lavey II, *Forty-Three Million Strong: An Overview of Civil Rights Protection for Persons With Disabilities*, 70 MICH. BUS. L.J. 548 (1991); Susan Sturn, *A Normative Theory of Public Law Remedies*, 79 GEO. L.J. 1355 (1991).

²²⁰ See, e.g., *Blom v. N.G.K. Spark Plugs (U.S.A.), Inc.*, 4 Cal. Rptr. 2d 139 (Ct. App. 1992); *Citizens for Responsible Behavior v. Superior Court*, 2 Cal. Rptr. 2d 648 (Ct. App. 1991);

specifically to those individuals who "historically, society has tended to isolate and segregate . . . and . . . such forms of discrimination . . . continue to be a serious and pervasive social problem."²²¹ This is easily demonstrable with infants with AIDS. Furthermore, because the ADA applies to "health services,"²²² the only issue is whether infants with AIDS "participate in, and contribute to, society."²²³

The potential for an infant with AIDS to participate in or contribute to society is the matter of much ethical, moral and legal debate.²²⁴ Most recently, a United States Court of Appeals addressed the issue.²²⁵ The case concerned Baby K, an infant girl, born with a congenital malformation in which a major portion of the brain, skull and scalp are missing.²²⁶ She has no cognitive abilities. She cannot see, hear or otherwise interact with her environment.²²⁷ Physicians attending the infant recommended no aggressive treatment because it would serve no therapeutic or palliative purpose. Instead, they "recommended that Baby K only be provided with supportive care in the form of nutrition, hydration, and warmth . . . [and] the possibility of . . . the withholding of lifesaving measures in the future."²²⁸ The mother insisted the infant receive mechanical breathing assistance whenever the infant needed it, and the physicians did not wish to comply. Thus, the issue was whether

Coca Cola Bottling Co. of Los Angeles v. Superior Ct., 285 Cal. Rptr. 183 (Ct. App.), *modified, reh'g denied*, 286 Cal. Rptr. 855 (Ct. App. 1991); Sanchez v. Lagoudakis, 486 N.W.2d 657 (Mich. 1992); Rose City Oil Co. v. Missouri Comm. on Human Rights, 832 S.W.2d 314 (Mo. Ct. App. 1992); Petri v. Bank of New York Co. Inc., 582 N.Y.S.2d 608 (App. Div. 1992) (holding that asymptomatic HIV infection was disability within meaning of the Human Rights Law, and plaintiff sufficiently stated claim that he suffered discrimination because of the others perception that he had AIDS); Tijerina v. City of Tyler, 822 S.W.2d 799 (Tex. Ct. App. 1992); Sentara Leigh Hosp. v. Nichols, 414 S.E.2d 426 (Va. Ct. App. 1992).

²²¹ 42 U.S.C. § 12101(a)(2) (1994).

²²² 42 U.S.C. § 12101(a)(3) (1994).

²²³ 42 U.S.C. § 12101(a)(7) (1994).

²²⁴ See Crossley, *supra* note 56, at 1618-30; see generally George P. Smith, II, BIOETHICS AND THE LAW: MEDICAL, SOCIO-LEGAL, AND PHILOSOPHICAL DIRECTIONS FOR A BRAVE NEW WORLD (1993); George P. Smith, II, FINAL CHOICES: AUTONOMY IN HEALTH CARE DECISIONS (1989); George P. Smith, THE NEW BIOLOGY: LAW, ETHICS AND BIOTECHNOLOGY (1989); George P. Smith, MEDICAL-LEGAL ASPECTS OF CRYONICS: PROSPECTS FOR IMMORTALITY (1983); George P. Smith, ETHICAL, LEGAL AND SOCIAL CHALLENGES TO A BRAVE NEW WORLD (1982); George P. Smith, GENETICS, ETHICS AND THE LAW (1981).

²²⁵ See *In re Baby "K,"* 16 F.3d 590, 593 (4th Cir. 1994).

²²⁶ *Id.*

²²⁷ *Id.* at 595.

²²⁸ *Id.*

the physicians were required "to provide respiratory support or other aggressive treatment."²²⁹

The physicians at the hospital in which Baby K was receiving treatment admitted that the Emergency Medical Treatment and Active Labor Act²³⁰ (EMTALA) required them to provide respiratory support in the "usual" situation. Nonetheless, seeking to withdraw treatment from the infant, the hospital argued, in part, that "an interpretation of EMTALA that requires a hospital or physician to provide respiratory support to an anencephalic infant fails to recognize a physician's ability . . . to refuse to provide medical treatment that the physician considers medically or ethically inappropriate."²³¹ Also, to provide respiratory support to Baby K would "provide treatment outside the prevailing standard of medical care."²³²

In holding that the hospital and the attending physicians must provide the respiratory support, the court recognized "the dilemma facing physicians who are requested to provide treatment they consider morally and ethically inappropriate"²³³ or "medically or ethically inappropriate,"²³⁴ but the Congressional statute provided for no such exceptions and mandated treatment. Thus, the court refused to consider the ethical considerations on a case-by-case basis. The Congressional statutory mandate justified treatment of infants considered to be beyond the ability to participate in or contribute to society. While the dissent wanted to allow inquiry into "this sensitive, private area,"²³⁵ the majority applied the statute strictly.

The Baby K decision involves the complex issue of an infant and his or her ability to participate in and contribute to society. In the case of Baby K, the statute protected the infant. Presumably, in light of the Supreme Court's refusal to hear the case on appeal,²³⁶ efforts are underway to amend the statute to exclude protection. But for children with HIV, AIDS, or a host of other maladies the health care system is unlikely to address, the legal responsibility of society is much stronger. That is, selective non-treatment is victimizing children. Litigation seek-

²²⁹ *Id.* at 592.

²³⁰ 42 U.S.C.A. § 1395dd (West 1992).

²³¹ *In re Baby "K,"* 16 F.3d at 592.

²³² *Id.*

²³³ *Id.* at 596.

²³⁴ *Id.*

²³⁵ *Id.*

²³⁶ *Mitchell v. Allstate Life Ins.*, 115 S. Ct. 70 (1994).

ing to provide protection results from statutes such as the ADA, or the Rehabilitation Act of 1973 or any applicable state statute that federal regulation does not preempt.²³⁷ Inclusion of children within Medicare would best preempt this litigation.

C. Moral Responsibility

Beyond the legal rights of the individual and the obligations of the state, there are the moral considerations that underlie human society. Because the issue under consideration involves children who are born into a cycle of discrimination, racism and poverty, one can argue that children are the least among the rest and thus are especially deserving of moral consideration. That is, cognizance must "address the moral adequacy of justification for selective nontreatment"²³⁸ of vast numbers of children without adequate health care. With limited resources and—at present—poor quality of life and often a relatively short life span, is it moral to withhold treatment?²³⁹ Is it moral to use limited resources to provide it?

Many persons and institutions, when confronted with the congenital malformation of Baby K, would decide that treatment absolutely is required. The ability of such persons to mobilize sufficient legislative support to provide treatment is their best recourse.²⁴⁰ Others would apply a case-by-case balancing. For example, "decision-makers should seek only to further the infant's own interests and should reevaluate treatment decisions as accumulated information lends greater certainty to the nature of those interests."²⁴¹ There is a presumption of possibility approach implicit in reevaluating treatment. "In light of . . . uncertainty, erring on the side of providing treatment that might enable a

²³⁷ State legislatures exercise considerable control in regard to termination of life support of persons able to make the determination. See *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990). See also for guidelines *Bellus v. State*, 843 P.2d 119 (Colo. Ct. App. 1993); *In re Kristopher M.*, 1992 W.L. 26783 (Conn. Super. Ct. Feb. 10, 1992); *Sanchez v. Lagoudakis*, 486 N.W.2d 657 (Mich. 1992); *City of Clayton v. Missouri Comm'n on Human Rights*, 821 S.W.2d 521 (Mo. Ct. App. 1991); *Petition of Dunlop*, 604 A.2d 945 (N.H. 1991); *Petri v. Bank of New York Co., Inc.*, 582 N.Y.S.2d 608 (App. Div. 1992).

²³⁸ Crossley, *supra* note 56, at 1589.

²³⁹ For a discussion of the issue, see *id.* at 1581.

²⁴⁰ In the majority opinion requiring the hospital to provide respiratory support to Baby K, the court emphasized that if persons or institutions objected to its interpretation of the federal statute, the proper recourse was seek redress in Congress. *In re Baby "K."*, 16 F.3d 590, 592 (4th Cir. 1994).

²⁴¹ Crossley, *supra* note 56, at 1629.

child to enjoy many years of life seems preferable to erring on the side of letting the infant die as a result of nontreatment."²⁴² Such an approach imitates the words of Saint Paul that if you are going to err, err on the side of kindness.²⁴³ It also reflects the physicians' oath: First, do no harm.²⁴⁴

The National Conference of Catholic Bishops also have taken a balancing approach. Writing in *Nutrition and Hydration: Moral and Pastoral Reflections*, the United States Catholic Bishops recognize that, "[t]he Judeo-Christian moral tradition celebrates life as the gift of a loving God, and respects the life of each human being because each is made in the image and likeness of God."²⁴⁵ But, "this does not mean that all possible remedies must be used in all circumstances. One is not obliged to use either 'extraordinary' means or 'disproportionate' means of preserving life—that is, means which are understood as offering no reasonable hope of benefit or as involving excessive burdens."²⁴⁶ On the other hand,

Decisions regarding human life must respect the demands of justice, viewing each human being as our neighbor and avoiding all discrimination based on age or dependency. A human being has a "unique dignity and an independent value, from the moment of conception and in every stage of development, whatever his or her physical condition." In particular, "the disabled person (whether the disability be the result of a congenital handicap, chronic illness or accident, or from mental or physical deficiency, and whatever the severity of the disability) is a fully human subject, with the corresponding innate, sacred and inviolable rights" First among these is "the fundamental and inalienable right to life."²⁴⁷

And yet, the advocates for life who insist upon providing treatment for infants like Baby K or the thousands of other infants or children afflicted with terminal and hopeless afflictions must mobilize their efforts to address the throng of other children equally in danger from non-treatment. That is, moral responsibility for treatment of terminal cases must expand to include moral responsibility for those far less ter-

²⁴² *Id.* at 1598.

²⁴³ 2 *Kings* 12:19.

²⁴⁴ reprinted in TOM L. BEAUCHAMP ET AL., *PRINCIPLES OF BIOMEDICAL ETHICS*, 330 (3d ed. 1989); WEBSTERS NEW WORLD DICTIONARY, UNABRIDGED, 1071 (6th ed 1994) (describing the Hippocratic Oath (Hippocrates 1620)).

²⁴⁵ COMM. FOR PRO-LIFE ACTIVITIES, NAT'L CONFERENCE OF CATHOLIC BISHOPS, *NUTRITION AND HYDRATION: MORAL AND PASTORAL REFLECTIONS* 1 (1992).

²⁴⁶ *Id.* at 2.

²⁴⁷ *Id.*

minal but just as gravely in danger from selective non-treatment. If a child—any child—lacks adequate health care, either because the system concludes the case is terminal or because the system says it will cost too much, the child in either case still lacks health care. This is immoral. Inclusion of children within Medicare is a moral responsibility.

VI. CONCLUSION

If America is serious about the health of its children, it is impossible to argue that the inclusion of children within Medicare would make no difference. The difference it would make would be enormous. We know this because of the difference it has made in the lives of America's elderly. Imagine if each American child had:

(1) Inpatient hospital care—all reasonable expenses for the first 60 days minus a deductible (\$696 in 1994). For the next thirty days, a coinsurance amount is deducted (\$174 in 1994), and after 90 days a child would be able to draw upon a 60 day lifetime reserve for a coinsurance amount of \$348 (in 1994) for each reserve day.

(2) Skilled nursing facility care.

(3) Home health care provided to persons who need skilled nursing care, physical therapy or speech therapy on an intermittent basis.

(4) Hospice care.

(5) Doctor's services to include surgery, consultation, and home office and institutional visits.

(6) Other medical and health services providing laboratory and other diagnostic tests, X-ray and other radiation therapy, outpatient services at a hospital, rural health clinic services, home dialysis, supplies and equipment, artificial devices (other than dental), physical and speech therapy, and ambulance services.²⁴⁸

Instead, "although the United States has the most expensive health care system in the world, it does not ensure even the most basic health care coverage for all of its children."²⁴⁹ This disparity is particularly onerous because it is compounded by the fact that many of these children suffer discrimination, are stigmatized by racism and are victimized by poverty. An examination of the resources expended for services associated with HIV/AIDS justifies the conclusion that children suffer discrimination from denial of protocol involvement, scarcity of

²⁴⁸ GREEN BOOK, *supra* note 10, at 130 (listing a partial list of Medicare benefits).

²⁴⁹ CHILDREN'S DEFENSE FUND, THE STATE OF AMERICA'S CHILDREN: YEARBOOK 1994 9 (1994).

drug therapies and more likely, selective non-treatment upon the onset of opportunistic infections. Racism in treatment of persons with HIV/AIDS also is documented. "Such barriers to care for young blacks contrast with the care received by the predominantly white, middle-class gay community, which has organized support systems through which medical care is actively sought, particularly in the early stages of the disease."²⁵⁰ And poverty is correlative: "While median household income was the variable most strongly associated with higher cumulative AIDS incidence specific to zip code, this association was most marked in zip codes with high percentages of persons who were black and who lived in multifamily units."²⁵¹

To ignore the present predicament of children is no longer responsible, especially with the defeat of any current federal health care reform package. A number of specific arguments can be made for the inclusion of children within Medicare. Among these is that cost and dire warning over the future of Medicare expenditures cannot decide the debate. Rather, Congress needs to address legislative remedies, such as raising the age limit for entitlement of the elderly, additional taxes on products such as tobacco, alcohol and gasoline, and a study of state initiated programs.²⁵² A remedy is justified because healthy children can make a financial contribution in the future, they have not received their due financial contribution in the past and, as is seen in statistics concerning HIV/AIDS, they receive a disproportional amount of community service today.

Cases such as Baby K in Fairfax County, Virginia and others concerning selective non-treatment for infants and children involve statutes designed to provide a protection for those who are most terminally ill. Yet arguably litigation under statutes such as the ADA would become less vehement if all perspectives on the issue of children's rights mobilized for the inclusion of children within a health care system that has proven itself beneficial to America's elderly. Baby K is one child, but there are many others suffering from selective non-treatment.

The issue of health care for America's child is a moral issue. More often than not, law is an inadequate remedy to immorality. However, in this instance, Congress should amend the law to include America's

²⁵⁰ Richard D. Moore et al., *Racial Differences in the Use of Drug Therapy for HIV Disease in an Urban Community*, 330 NEW ENG. J. MED. 763, 767 (1994).

²⁵¹ Hu, *supra* note 79, at 23.

²⁵² YEARBOOK, *supra* note 38, at 13-15.

children within Medicare because it is a proven conduit to the essential issue: Does America want healthy children and thus healthy adults?

